Developing shared understandings of multi-agency working with adults who self-neglect

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Abstract

The Care Act 2014 imposes a duty on local authorities to make statutory safeguarding enquiries when they suspect that an adult with care and support needs is self-neglecting. The Act also imposes a duty on local authorities and relevant partners, such as health and housing, to work in partnership. However, safeguarding adult reviews and government ombudsman investigations have shown a consistent failure of agencies to work together on cases involving self-neglect. The aim of this research is to develop an understanding of how multi-agency working in self-neglect cases can be improved, whilst respecting the autonomy of service users who self-neglect.

This research applies the methodology of professionalising action research in a new setting, that of multi-agency working in the public sector. It is the first study to include the views and input of the full range of agencies who might typically work with people who self-neglect. Following a pilot project, fifteen different professional groups from two local authorities in the North of England were identified, who work with people who are self-neglecting. More than 30 group interviews were carried out with these staff in the problem-sensing phase of the action research, to identify priorities for change. Subsequently, two multi-agency workshops were held in each local authority, involving a total of 120 staff from the various agencies, to identify how change could be implemented.

The research provides important insights into how practitioners assess the effectiveness of working together in this complex and demanding area of practice. A key message from the research is the extent of the disarray in multi-agency working, and the research extends the discourse on multi-agency working in four main areas of difficulty; inter-agency conflict, inter-agency communication, professional role understanding, and achieving change in multi-agency working. New findings in the research challenge assumptions about how practitioners from a wide range of agencies operationalise the Mental Capacity Act 2005 in relation to people who self-neglect. Overall, rich insights into working practices emerge, and the author gives recommendations for changing and improving multi-agency working with people who self-neglect. Furthermore, using a professionalising action research approach allowed solutions to be identified by participants, which have begun to be translated into practice.

Abbreviations

AR	Action research
DoH	Department of Health
DSM	Diagnostic and Statistical Manual of Mental Disorders
LASS	Local authority social services
LSAB	Local Safeguarding Adults Board
SAR	Safeguarding Adults Review
MASH	Multi-agency safeguarding hubs
MCA	Mental Capacity Act
RiPFA	Research in Practice for Adults
RCP	Royal College of Psychiatrists
SIPR	Scottish Institute for Policing Research
SCIE	Social Care Institute for Excellence
SfC	Skills for Care

Presentations

9.10.19: Westminster Insight Conferences, Safeguarding Adults Conference, London. *Exploring organisational approaches to self-neglect to promote good practice* (Oral presentation)

8.10.19: Bromley Safeguarding Adults Board, Adult Safeguarding Conference, Hayes, London. *Developing shared professional understandings of self-neglect and multi-agency interventions* (Oral presentation and workshop)

13.5.19: Annual Safeguarding Conference, Association of Directors of Adult Social Services North West, Manchester. *'Self-Neglect': A Guide to Working with Complex Cases'* (Oral presentation)

29.10.18: Developing and Improving Adult Support and Protection in Scotland, National Conference, Edinburgh, Scotland. *'Person-centred practice, self-neglect and multi-agency working'* (Oral presentation)

10.9.18*:* Self-Neglect and Adult Safeguarding, National Conference, London. *'Developing shared professional understandings of self-neglect and multi-agency interventions'.* (Oral presentation and workshop)

20.10.17: Collaborative Action Research Network (CARN) Conference, Rethymno, Greece. *'Conflict, caring and change: Professionalising action research with health and social care staff in two local authorities in England'.* (Oral presentation)

25.9.17: Self-Neglect and Adult Safeguarding, Healthcare Conference, London. *'Developing shared professional understandings of self-neglect and multi-agency interventions'.* (Oral presentation and workshop)

13.9.17: Action on Elder Abuse National Conference, London. *'Natural growth or clumsy graft? Does self-neglect 'fit' as part of adult safeguarding?'* (Oral presentation and workshop)

8.6.17: Festival of Research, LJMU. *'Avoiding Wimbledon syndrome: proxemics, focus groups and the implications for researchers and their research'.* (Oral Presentation)

24.3.17: Cheshire & Wirral Partnership NHS Foundation Trust, Research Conference. *Developing shared professional understandings of self-neglect and multi-agency interventions: How can we change the way we work together to support people who self-neglect? (Oral presentation)*

Publications

Aspinwall-Roberts, E (2017). Why we have missed an opportunity to tackle self-neglect. *Community Care,* 2.3.2017. Available from: http://www.communitycare.co.uk/2017/03/02/missed-opportunity-tackle-self-neglect/

Publications

[redacted] Safeguarding Adults Board

In conjunction with

LIVERPOOL
JOHN MOORES
UNIVERSITY

The Short Guide to Working with People in Circumstances of Complex Self-Neglect

The Short Guide to Working with People in Circumstances of Complex Self-Neglect

Who is it for?

For all professionals working in complex self-neglect situations.

What is it designed to do?

- To help you make defensible decisions
- To give you suggestions about what you can do in difficult situations, based on the experience and insights of other professionals in [redacted] working with people who self-neglect
- To make sure you, and all the other agencies you work with, have tried everything you possibly can.
- To help you put together the pieces of the multi-agency puzzle

With thanks to:

All of the staff from many different agencies, across [redacted] who came to the self-neglect workshops held at Liverpool John Moores University during 2018. Discussions and ideas from these workshops led to this short guide being compiled.

The [redacted] Peer Support Group who read, commented on, and made additions to this guide.

“As Independent Chair of the Safeguarding Adult’s Board I am pleased to introduce this Practice Guide for colleagues of all agencies working with people who self-neglect within the Boards area. I hope you find the Guide helpful, as we have spent the last year developing it with a wide range of colleagues from many different agencies and consulting with people who self-neglect, to make sure that it is relevant and useful in your day to day work.

Responding to self-neglect can be a complex and difficult area of your work, and there has been a range of academic interest in the causes of, and outcomes for, people who self-neglect. But what I have been encouraged by is some of the very practical suggestions within this Guide, as well as the shared sense of purpose by a wide variety of agencies to try to engage and improve the wellbeing of people who self-neglect.

I have also been impressed by the way in which colleagues from the different agencies involved in the development of this Guide, have recognised that the challenges they experience individually in working with people who self-neglect, are shared across all agencies, and that it is only by working together in partnership that we can really make a difference.

I know that one of the challenges of working with people who self-neglect can be your own agencies processes, as understandably resources and time can be limited by the demands placed on each of your organisations, but I hope that this Guide gives you confirmation that you are not alone, and gives you confidence in conversations with your colleagues and managers about what helps when you are trying to engage with someone who self-neglects.

In developing this Guide, I was mindful that the Safeguarding Adult Board has a responsibility to prevent abuse and neglect in its area and to understand the experiences of staff working with people who self-neglect, and while I acknowledge that each of your organisations will have its own procedures and processes, it is an expectation that these will be compatible with this Guide”.

Contents

Useful things to remember when working with people in complex cases of self-neglect

Show curiosity, interest and concern about people's welfare.

Relationship building is crucial. Be patient and work at their pace.

Find out what the person wants and expects, and what is worrying them, see if they feel able to cope or resolve some things for themselves.

Identify whether any risks (or worries) require immediate action – what is the duration and seriousness of the self-neglect. Are the problems low, medium or high risk?

Try to understand the history of how they came to be self-neglecting, and their worldview – what is their life like? Consider trauma, bereavement, loss, divorce. Be aware of any diversity issues.

At the right point be open and honest with the person (particularly about what your worries are about them). Reinforce the positive aspects of their life.

Identify the supports that might be out there for them.

Offer choices, but don't make promises you can't keep, don't over-promise.

Call a case conference or professionals meeting early on in the process. Share the risk.

Everyone (including you manager) needs to understand that persistence and commitment require time.

Work on shared goals, not goals based on how you think they should live.

Proportionality is everything. Don't use a sledgehammer to crack a nut.

Persist, don't give up, keep going back, but make sure your involvement is lawful.

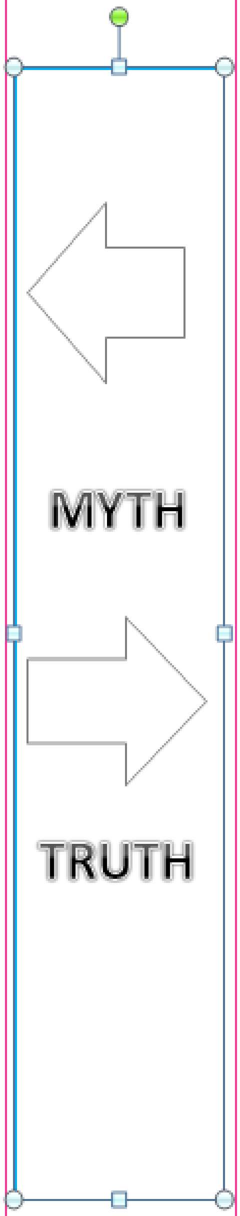
Liaise with other professionals, and where possible the adults family and friends, give thought to who else could usefully be involved.

Negotiate 'quick wins' for the person – possibly leading to 'bargaining'.

Remember human rights!

The term 'self-neglect' can be perceived as a very stigmatising and emotive term – be careful how you use it.

Myth busting about self-neglect and what agencies can do



Myth: We (social worker, nurse, psychologist, occupational therapist, mental health team etc) can wave a magic wand	**Truth:** We can help but the person needs to engage with what is offered
Myth: Medication and therapy can provide a quick solution	**Truth:** Improving well-being, quality of life or neglectful behaviour can take a long time
Myth: Safeguarding will sort everything out ('an easy referral can make this person safe')	**Truth:** It's a team effort. It requires a multi-agency approach to work with complex cases
Myth: If a safeguarding referral is made, the social worker can enter a person's home and remove self-neglecting people from their property	**Truth:** Social workers are unable to remove someone from their property without consent or a court order or legally prescribed process
Myth: People can be forced to engage in person care task and have support from care agencies. Staff can 'just do it' for the person to fix the problem	**Truth:** A person has to consent to personal care being undertaken. If someone has capacity they have the right to make unwise decisions
Myth: If a person refuses help, such as with de-cluttering of clearing we can force them to accept it	**Truth:** It is all about negotiation and understanding why they are saying no, and an attempt to reach a shared goal so some support can be delivered and the risk reduced.
Myth: Social workers can over-ride someone's decision when they have capacity	**Truth:** They can't nobody can
Myth: Social workers have powers of surveillance	**Truth:** They don't
Myth: Only doctors can assess mental capacity	**Truth:** A range of people can assess capacity, depending on how well they know the person and what the decision is that needs to be made
Myth: Patients cannot be discharged from hospital if their property is not in a good State	**Truth:** They can
Myth: If we clean the house out, the problem will be sorted	**Truth:** The behaviour probably won't change
Myth: Self-neglecting people are lazy and it's a 'lifestyle choice'	**Truth:** Situations can be very complex, and it may be choice in some elements of the adult situation but not necessarily all
Myth: Self-neglect is about hoarders	**Truth:** Self neglect includes lots of other factors – such as not managing personal care or medication, not paying bills or eating property. Many people who hoard don't self-neglect at all

What can different agencies do for people who self-neglect?

Clinical psychologists can support people who self-neglect by developing a psychological understanding of their situation and helping them to find strategies to help manage their situation, including psychological therapy

Community nurses provide healthcare to people in their own homes. They will refer to other services, such as the Continence Service, or for specialist equipment like hospital-type beds.

Environmental Health aim to reduce the risk to the self-neglecting person themselves but also to the community, through practical direct work with the person, invoking relevant legislation where necessary.

Fire & Rescue Services can provide fire safety advice and put practical measures in place to reduce the risk of a fire. They may refer on to other agencies for more support.

General Practitioners (GPs) can identify people who seem to be self-neglecting, provide support and refer to other agencies to enable people to get support and help if required and consented to.

Hospital nurses will identify patients who seem to be self-neglecting, support the patient and refer to other agencies to enable patients to gain help and support if required and consented to whilst in hospital.

Housing staff can help people very practically to support their tenancies if they are at risk of being evicted because of problems with self-neglect or hoarding.

Independent Advocates support the person to make their own decisions, ensures their views, wishes, feelings, beliefs and values are listened to, and may challenge decisions that they feel are not in the person's best interests.

Occupational therapists work with individuals to identify any difficulties they experience in day to day living activities, and finding ways to alter or solve them. They support independence where possible and safety within the community, and build confidence and motivation.

Paramedics are called by the patient or a third party caller due to medical concerns or health deterioration. They will deliver appropriate emergency treatment, assess mental capacity in relation to the health issues presented (particularly if a person is refusing to go to hospital), and refer on to other agencies with concerns.

Physiotherapists can help with treatment of injury, disease and disorders through physical methods. A physio helps and guides patients, prescribes treatment and orders equipment.

Police can investigate and prosecute if there is a risk of wilful neglect, they can provide safeguarding to families and communities by sharing information, refer to specialist partner agencies, and use force to gain entry/access if there are legal grounds to do so. The PCSO Early Help Team will refer to other agencies and signpost.

Probation case managers will identify problems via home visits and provide regular monitoring. They may refer on to social services, mental health services, housing, health etc. They will complete risk assessments and risk management plans, making links to the risk of serious harm.

RSPCA investigate complaints of cruelty and neglect to animals and offer support and advice.

Social workers will complete an assessment by taking to and getting to know the person. They may establish their mental capacity to make particular decisions about their lives, look at all of the options. They may put in a package of care, or refer to other agencies for the services that they provide (for example, to fire services for a fire safety check). They might arrange multi-agency meetings to discuss concerns and ways forward. They can help with relationship building and communication skills, and try to develop support networks.

Voluntary, Community and Faith Sector (VCFS) staff and volunteers can provide a whole range of social opportunities and support services that can connect people with their communities, e.g. luncheon clubs, support groups. Health advise, furniture recycling, food banks, advocacy etc. Staff and volunteers can be a key part of formal as well as informed plans and support.

What professionals think an adult who self-neglects might hope (and fear) when they arrive in their lives:

The Mental Capacity Act 2005 – 11 things to think about

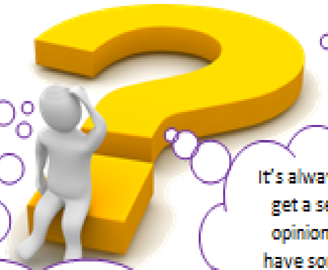
A person MUST satisfy the two-stage diagnostic test before you can make a decision about their capacity. So they must have an impairment of the mind or brain, and it must be enough of an impairment to mean that they can't make a particular decision at this particular time. If they haven't got impairment, then why are you testing their capacity?

Just because someone has an impairment, doesn't mean they lack capacity!

You need to be really clear about what the specific decision is that needs to be made. You must establish what the decision is that the person needs to make, so that you can confidently say 'this person does or doesn't have capacity to make this particular decision at this particular time'.

People who do have capacity may still need support. They may still be living in a desperate, risky, unhappy situation that we could try to help do something about, and we still have a duty of care.

Refusal of treatment does not necessarily indicate a lack of capacity



Indecision or avoidance should not be confused with lack of capacity

It's always ok to get a second opinion, and have someone else in the room

Good recording is essential, particularly in the case of 'unwise or eccentric' decisions

People have a right to make 'unwise decisions'. If it's a significant change from their usual opinions or previously stated wishes you might want to clarify things, but in itself it doesn't mean they have not got the relevant mental capacity.

You must be satisfied that you have fully discussed the risks in a situation, so that the person has the information they need to understand, retain, and use and weigh information about their situation. Otherwise, how can you possibly know that the person has really thought about all of the information that is pertinent to the decision to be made?

On the other hand, if a person lacks capacity, it's not a 'done deal'. It doesn't mean they can be spirited off to a residential home, for example. You have to have a very, very good, legally sanctioned reason for removing a person from their home. If a person lacks capacity then the least restrictive option should be the first to be considered

Executive and decisional capacity – think about whether this is this worth exploring further with people who self-neglect

Mental capacity involves not only the ability to *understand* the consequences of a decision, (decisional capacity), but also the ability to *execute*, or carry out, the decision, (executive capacity).

A simple way to demonstrate this is to use 'tell me/show me' approaches. Ask the person to 'tell you' how they do something, and then ask them to 'show you' how they do it.

Here are some suggestions from practitioners about how this could be done

- You need to observe the person's practical ability to complete actions relating to a decision such as cleaning, shopping or cooking. For example, a person may say they are able to make meals, no problem, but you can't see any evidence that meals are being prepared or cooking done. You could ask them to show you how they make a cup of tea, or a slice of toast.

- Sometimes, people have physical difficulties with completing an action. For example, a person may say they are able to take their medication independently. But when you look at the medication blister pack it is unopened. It may simply be that the person is unable to open the blister pack unassisted.

- A person may have the ability to self-medicate, but make the decision not to take the necessary medication as they fear the side effects (such as frequent urination), or they lack confidence in its efficacy.

- It may be hard to separate out embarrassment, avoidance, or the person just changing their mind from 'decisional incapacity' as they can be almost identical in how they present. People who self-neglect may have compounding factors.

- In hoarding situations, a person may have the ability to clean up or order a skip, but that doesn't take into account the related emotions – the value of their possessions to them, emotional significance of the items, safety, anxiety or guilt.

- Decisional and executive capacity may be difficult to test in some environments, such as hospital. 'Testing' decisional capacity may require there to be a level of trust that comes from a more established relationship.

‘Have you tried?’ Common practice situations

Neighbours have raised concerns about Mr W – but he won’t let anybody in.

Have you tried?

Before you go out, think about:

- Are you the ‘preferred professional’ for this person? If not, who is?
- Is it necessary to meet at home? Where else do they go? Can you meet them outside the home in a neutral non-threatening place – GP surgery? Café? Pub?
- Would they like to bring a friend or have a friend present when you visit?
- Can a family member or neighbour introduce you?
- Texting people directly in advance of your visit to re-assure them
- Agreeing a ‘secret knock’ with the person if they are concerned about letting people in
- Be discrete, because the person doesn’t want to lose face with their neighbours
- Joint visits with referrer or someone they trust (e.g. CPN if they are known)
- Think about what other services are likely to have contact with the person, such as the Fire service, Housing, utility companies. Can you do a joint visit?
- Can you enlist the help of faith, voluntary and support services, Church leaders etc.
- Can you make an appointment, by phone or letter, rather than just turning up?
- Can you build rapport before the visit on the phone?
- If the person is known, use your previous experience? What has worked or failed before?

When you go out:

- Plan what you are going to say ahead of time
- Don’t wear a uniform if at all possible
- Don’t go ‘suited and booted’, in masks etc. - need to build rapport before that
- Consider what can be offered to make things better?
- Be open and honest about why you are there.
- Be informal
- Getting in does not necessarily mean getting on - engage, engage, engage
- Do not be oppressive and forceful
- Are there little opportunist things you can make the most of? Offer to buy milk!
- Approach from a positive not a critical angle
- Be conscious of your body language and compromise yourself sometimes, so you don’t make people feel uncomfortable

If you fail to get in:

- Revisit all of the points above
- Be persistent
- Try cold calling
- Put a note through the letterbox, giving another time when you will call back
- Put a note through the letterbox asking Mr W to phone you
- Use predictable crisis events
- Contact police if the person has not been seen for some time, or if there are any concerns.

Finally, Mr W has let you in, but is very uncommunicative and suspicious

Have you tried?

Introduction (the first 5 minutes is *very* important)

- Asking Mr W to show you how he does things around the house
- Starting with safe conversations using visual clues– look at family photos, ask about hobbies, what are you having for tea, etc.
- Trying to not show your opinions or being judgemental
- Looking for positive avenues and topics of conversation and developing them
- Trying to find a common interest
- Don't try to get things done, do nothing, just chat …can be very different from normal visits
- Don't make promises you can't keep, be honest, right from the start

The assessment

- Identifying a health/care need and possible solutions which Mr W is agreeable to
- Asking if you can contact family/carers
- Checking entitlements and other services/agencies available
- Offering good choices.
- Creating outcome focussed assessments with Mr W
- Setting realistic SMART goals
- Focussing on risks rather than telling Mr W how to live.
- Thinking about the consequences of risks and be honest
- Making sure the action plan and reviews are created by Mr W
- Working with him, not doing it to him
- Trying a staged approach, not doing everything at once
- Celebrating successes
- Thinking about your verbal and non-verbal approach, be an active listener

Practical support

- Offering support on a trial basis
- Considering any other sources of help such as family members
- Are there any immediate agreed actions (quick wins?)
- Working with Mr W to establish his priorities in terms of needs
- Always try to have another option
- Going at the person's pace when supporting them to move or remove items, otherwise it may feel chaotic to the person.
- If you are going to offer a skip (the dreaded 'S' word'), is it because all the items are broken? Can some be recycled instead?
- Just because someone has a lot of items doesn't mean they are unhygienic
- Remembering that the meaning attached to items is logical to the individual
- It's okay to dangle carrots when you've considered different approaches.
- Educate … health, safety, support
- Emphasising the positives
- Persuading managers to waive individuals' financial contributions, if this appears to be the main obstacle to ongoing intervention
- Looking for support groups and peer support

Best Practice with people who self-neglect and don't want to engage with services

Find out if the adult may be in need of care and support and offer assessment, and if eligible, provide care and support services; If they refuse to engage then;

Complete a mental capacity assessment if you can, which should be time and decision specific
If the adult refuses to engage, gather as much information as possible to inform decision

Complete a risk assessment, ideally with the adult if you can
If the adult refuses to engage, gather as much information as possible to inform the assessment and decision making, then;

Consider whether there is any legal basis to intervene further. At this point you may need to seek advice

It may be reasonable not to intervene further, as long as no-one else is at risk, and the adults 'vital interests' are not compromised (immediate risk of death or serious harm, or whether a crime has been committed, or evidence of coercion)

There needs to be clear, documented attempts to discuss this with the adult in order to make sure that all decisions are fully explained and recorded, and support them to:

- Weigh up the risks and benefits of different options
- Be aware of the level of risk and possible outcomes
- Agree on the level of risk they are taking (including their capacity to take that risk)
- Offer advocacy or other appropriate support

If the adult continues to refuse to engage, and there are still worries, then;

Record your reasons for not intervening or sharing information, including every detail of your assessment of the person's capacity and of your conversations with them about the potential risks posed by their chosen action

Review the situation regularly
Communicate (ideally in writing if appropriate) with them, making sure that they understand where they can go if they want to seek help in the future

Make sure that other agencies have been informed and involved as necessary

This means that after all reasonable and proportionate attempts to engage are exhausted, and other agencies have been informed or are involved with the adult, then the case may be closed.

Where there are no other agencies involved at the point of case closure, and the adult will be without any contact, it may be appropriate to discuss with senior management and consider regular contact with the individual via professional support, review or a care and support package. The frequency and duration should be proportionate to the known presenting risks.

When to keep the person's case open….

Working with people who self-neglect, and building up a trusting relationship with them, can be a very slow, painstaking process. Consistency in terms of the worker who is involved and their approach to the adult is also very important. Practitioners taking part in our self-neglect workshops have told us that this sometimes doesn't sit well with timescales for closing cases and ending involvement.

For social workers especially, there can be pressure to close self-neglect cases, particularly if a service user is refusing to engage, and is deemed to have mental capacity. Yet often substantial worries remain about the self-neglecting person.

[redacted] Safeguarding Adult Board partner authorities have therefore agreed that in particular high-risk, complex self-neglect cases, involvement should continue and cases remain open. It is anticipated that the decision to keep a case open longer term than usual, will only apply to a small number of situations, and these will need to be monitored to make sure there are clear aims to continued involvement, rather than the case simply 'drifting' along.

It is really important to think about who is the best person to maintain direct involvement over a period of time, as this may not necessarily be a social worker. It may be a CMHN, a tenancy support worker from Housing, or an occupational therapist for example.

The following ideas will, we hope, help all partner agencies to make decisions about keeping cases open in the longer term.

Points to consider when deciding whether to keep a complex self-neglect case open to a worker

Every circumstance where an adult self-neglects is unique so there is not a formula in order to arrive at the 'right answer', but we think that there are eight key areas to consider.

We hope the ideas which follow will be a useful tool to use in supervision discussions for example and in assessments of when a case should remain open.

In making the decision for a case to remain open and active, you should consider:

1. The quality of information as to the circumstances

- The adults story and history – what have been major events in their lives, how have they been shaped by these and coped with them, what is important to them?
- Reliability and availability of information
- Existence of care and support needs
- Any changes to presentation, behaviour or routine
- The presence or absence of coercion
- Any previous family, community, housing or safeguarding concerns
- Awareness of the strength, availability and responsiveness of the adult's personal and local networks

2. The risks to the person, and to others

- Seriousness of the circumstances
- Risk of death or major harm
- The nature and timing of the risk
- Has it changed over time?
- Does the risk affect others, such as neighbours or other tenants?
- Are there any children involved?
- Has a crime been committed against the person?
- Consider your 'proportionality and perspective' about the circumstances.

3. The likelihood of the risk actually happening

- Immediate nature of the risk?
- Are all variables being properly weighed?
- Is there any objective or research evidence available?
- Consider the over-influence of the 'protection imperative' ("What's the point of making someone safe if in doing so you just make them miserable?" (Munby, LJ, 2007)
- Are you 'over-egging the risk pudding'?

4. The relevance of the Mental Capacity Act

- Consider mental capacity in order to do what? Remember any assessment must be issue and time specific
- If you are considering actions that could have a significant impact on the person, you need to be clear that it is the least restrictive option and necessary and proportionate to the presenting risk
- Have all practicable steps been taken to allow the adult to make the decision?
- Making an unwise decision is not the same as being unable to make a decision
- 'Lacking insight' could be simply be taking a 'different view' to that of professionals
- Have you thought about functional and executive capacity (tell me/show me)?
- Even if the person does not have the relevant mental capacity, their wishes and feelings should be considered and they must carry weight in your decision making

5. The efforts that have been made to engage with the self-neglecting person

- Intervening successfully depends on taking time to gain the person's trust and build a relationship, and going at the person's own pace. Have you done that? What evidence have you got that you are progressing?
- Using the relationship you have with the adult to make it possible for them to look after themselves
- Encouraging them to continue the conversation with other people who they trust
- Record your reasons for not intervening
- Include detail of your assessment of capacity and of your conversations about the potential risks posed by their chosen action
- All decisions should be fully explained and recorded
- Other agencies should be informed and involved as necessary
- Support the adult to weigh up the risks and benefits of different options
- Review the situation regularly and agree your approach with your manager
- Test out if the adult understands where they can go if they want to seek help in the future

6. The strength of the adults views

- What is the adult's rationale for their views or opinions?
- Is it consistently stated, or has it changed or developed over time?
- Is what they want to happen possible, lawful and does it impact on other people's rights?
- Is it legitimate or reasonable in the circumstances?
- Are they declining all support to help address needs, or just some?
- Can they demonstrate an ability to adapt to other changes in circumstances?
- The adult's rights to privacy and family life *could* outweigh concerns. You must consider the Human Rights Act.
- Different people give different weight to different factors or concerns – the person may simply not see the situation as being as serious as you do.

7. The steps necessary to reduce risk

- Would the steps taken to reduce the risk be lawful, necessary and proportionate to the risk?
- Consider the important balance between the adult's rights to life, freedom from inhuman treatment and from discrimination, with their rights to liberty, fairness and privacy
- Is the intervention proportionate to the need to protect from harm or the real possibility of future harm? If not, then without due care our efforts to safeguard a person may in themselves become abusive
- In most cases, a court must decide whether someone should be removed from their home against their wishes. You should not take certain steps without the sanction of the court. Your legal team can advise you further.

8. The likelihood of future engagement

- What are the real, known strengths, availability and responsiveness of the adult's support networks? Can they be strengthened or expanded?
- Is there organisational capacity to monitor and review the situation regularly?
- Are you assured that they understand where they can go if they want to seek help in the future?
- What is the best communication method for the person?
- Is there room for compromise, expediency, delay or better timing?
- Could someone else have more likelihood of successfully engaging with the person, and what a good outcome would look like?
- Have other agencies been informed and are they involved as necessary?
- The frequency and duration of any contact and efforts to engage should be proportionate to the factors above.

6. The strength of the adults views

- What is the adult's rationale for their views or opinions?
- Is it consistently stated, or has it changed or developed over time?
- Is what they want to happen possible, lawful and does it impact on other people's rights?
- Is it legitimate or reasonable in the circumstances?
- Are they declining all support to help address needs, or just some?
- Can they demonstrate an ability to adapt to other changes in circumstances?
- The adult's rights to privacy and family life *could* outweigh concerns. You must consider the Human Rights Act.
- Different people give different weight to different factors or concerns – the person may simply not see the situation as being as serious as you do.

7. The steps necessary to reduce risk

- Would the steps taken to reduce the risk be lawful, necessary and proportionate to the risk?
- Consider the important balance between the adult's rights to life, freedom from inhuman treatment and from discrimination, with their rights to liberty, fairness and privacy
- Is the intervention proportionate to the need to protect from harm or the real possibility of future harm? If not, then without due care our efforts to safeguard a person may in themselves become abusive
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Chapter 1: Introduction

1.1 Background to the study

1.1.1 The introduction of the Care Act 2014

In April 2015, a new and historically significant piece of legislation, the Care Act 2014, came into force in England. This Act repealed much of the legal framework addressing the welfare of vulnerable adults, which had been in place since the end of the Second World War, and which still strongly reflected the ideals of the Beveridge Report of 1942, and the post-war welfare consensus. The Care Act 2014, built around the primacy of the 'wellbeing principle' reflects the move towards personalisation, individualisation and 'responsibilisation' (Ferguson, 2007) which has been the direction of travel in statutory local authority services for nearly two decades, since the first New Labour administration of the late 1990s.

Despite its rather benign façade, the Care Act 2014 actually increases the legislative burden upon local authorities and their partner agencies, and this is particularly true in the area of adult safeguarding, which hitherto had not been a statutory duty, but merely a requirement set out in policy (*No Secrets*, 2000). For the first time in English legislation, the Care Act 2014 imposes a duty on Local Authorities to make statutory safeguarding enquiries, or direct others to make them, where they have cause to suspect that a person is experiencing abuse or neglect. The reach of safeguarding is also increased as domestic abuse, modern slavery and self-neglect have been introduced as 'new' types of abuse and neglect which can be investigated under the Care Act 2014. This can be seen as an example of 'juridification', that is, 'the tendency towards an increase in formal (or positive, written) law' (Habermas, 1987, p359).

The Care Act also imposes a new duty (S6) on local authorities and relevant agencies to work in partnership and 'co-operate generally' (Care Act 2014, p6). However, partnership working is not a new idea in health and social care, the Care Act 2014 simply expands the definition to include other ‘relevant’ agencies. Smith & Anderson (2008) argue that the development of partnership working between health and social care can be traced back to the 1980s, and the pre-occupation of the then Conservative government with efficiency, the inadequacies of state bureaucracies, and a concern for what was perceived as self-serving professional autonomy. Major enquiries into child and adult deaths appeared to show that failures of communication and silo working (Kaehne, 2017) were having profound consequences for service users. The advent of New Labour in 1997 added new impetus to the debate, and partnerships were an essential theme of the New Labour government’s ‘third way’ (Pinkney et al, 2008; Dickinson & Glasby, 2010; Cameron et al, 2014a). The 1997 White Paper, *The New NHS* emphasised the importance of collaboration across health and social care, centred on the needs of the patient (DoH, 1997) and collaborative working has continued to be highlighted in policy and legislation. In recent times, the Health and Social Care Act 2012, the Care Act 2014 and the NHS Five Year Forward View (DoH, 2014) all explicitly promote integrated care (Shand & Turner, 2019). Clements (2017) notes that, ‘Exhortations to organisations, professionals and other service providers to work together more closely and effectively, litter the policy landscape’ (p13). Dickinson (2014) adds that as a result, an industry has developed to support integration practice, all attempting to discover the ‘holy grail of person-centred, cost -effective and efficient services’ (Thomas, 2015, p199).

A literature review in 2014 (Cameron et al, 2014a) of factors that promoted or hindered joint or integrated working, found only tentative indications that such working could deliver the desired outcomes. They found the evidence to be ‘less than compelling’ (p62) and considered it did not justify the faith which successive governments have invested in it. The authors argued that the reasons why it was still attractive to the Government were threefold; increasing numbers of older people; greater numbers of people living in the community with complex needs; and the agenda of fiscal restraint espoused by the Government (ibid).

1.1.2 Adult safeguarding and multi-agency working

A demonstration of the increased impetus over the past few decades for ‘relevant agencies’ (Care Act, 2014) to work together, has been the development of the adult safeguarding agenda and the emphasis on multi-agency collaborative working in this area. Morris (2008, p167) defines multi-agency working as, ‘the arrangements and processes for a number of single agencies to come together to plan and deliver services that have shared aims and outcomes.’ This drive towards multi-agency working, propelled in part by a series of scandals and enquiries in the care of vulnerable adults, increasingly became evident in the national policy agenda of the 1990s (Williams, 2011). However, it was not until sometime later (Manthorpe et al, 2010) with the publication of the *No Secrets* guidance by the Department of Health in 2000, that collaborative working in adult safeguarding was made explicit in government policy. *No Secrets* did not introduce any specific or statutory requirement on agencies to work together (Pinkney et al, 2008), although local authorities were give the lead co-ordination role, and it was not perhaps the panacea it might have been expected to be. In 2008, the Serious Case Review of the Murder of Steven Hoskin noted that,

> ‘The safeguarding systems for children and adults are poles part in terms of profile, performance and working in partnership … safeguarding adults is a poor relation in terms of profile, funding and resources.’ (Flynn, 2008, p25).

1.1.3 Self-neglect as a safeguarding issue

The inclusion of self-neglect into the Care Act 2014 came as a ‘surprise, with many practitioners struggling to know the best way of managing and responding to such referrals’ (Fitzgerald, 2016, np). Including self-neglect in safeguarding is in itself a problematic concept, as abuse is generally defined as a situation involving a perpetrator and a relationship of trust (*No Secrets*, 2000; WHO, 2002; McDermott, 2008). Self-neglect has neither of these features. This has made it difficult for practitioners working in this area, because whilst the emphasis in policy was on harm perpetrated by others, agencies were uncertain when they should become involved in self-neglect cases, what their legal mandate was and how they should work collaboratively (Braye et al, 2015b).

The statutory guidance which accompanies the Care Act 2014, states that self-neglect, 'covers a wide range of behaviour, neglecting to care for one's personal hygiene, health or surroundings, and includes such behaviour as hoarding.' (Department of Health, 2016, p232). However, the guidance gives no detail of *how* practitioners should work with people who self-neglect (Carter 2014). Although the original guidance was revised in 2016, the revised section on self-neglect was described by one commentator as 'difficult to understand, let alone apply', and 'not helpful' (Fitzgerald, 2016). Safeguarding Adults Reviews (SAR's) commissioned where an adult has died or suffered serious harm, have shown a consistent failure of agencies to work together on cases involving self-neglect (Manthorpe and Martineau, 2011, 2016; Scourfield, 2010; Braye et al, 2013). Recent studies (Braye & Preston-Shoot, 2017; Preston-Shoot, 2017) have indicated that since the implementation of the Care Act 2014, roughly one third of SAR's have been in relation to self-neglect, which is a disproportionately high figure when set alongside other types of adult safeguarding such as physical or institutional abuse.

At the time of its inclusion into the Care Act 2014 as a safeguarding issue, a Department of Health spokesperson described self-neglect as "hugely challenging … a massively growing issue" (Crawley 2015, np).   Thus it is proving to be. The most recent safeguarding statistics available showed that in 2018/19 there were 7,790 cases of self-neglect investigated under the Care Act 2014 (NHS Digital, 2019). This is almost equivalent to the number of organisational abuse cases investigated, despite being a 'new' category of abuse, and strongly indicates that this is, indeed, a growing issue.   One aspect of this is that self-neglect, rightly or wrongly, is perceived as an issue mainly affecting older people. Demographically, the number of older people in the UK is forecast to rise exponentially within the next few decades, with the number of people age 65+ projected to rise by 40.7% in the next 17 years (Age UK, 2018). It can therefore be concluded that self-neglect will become substantially more significant (May-Chahal & Antrobus, 2012; Dong et al, 2012) for professionals who work in this area, and will have significant resource implications. However, Doron (2013) argues that the perspectives of professionals working with self-neglect have been little researched.

The current legal and policy developments suggest a reification of the concept of self-neglect, as self-neglecters become problematised as a safeguarding 'issue', legitimising intervention and potentially enabling professionals to override the autonomy of those who self-neglect. This raises the key question of how multi-agency working in this area can be successfully developed, particularly under the new legal framework, to ensure the best outcomes for adults who self-neglect.

1.2 Rationale for the study

Cases involving elements of self-neglect can be the most complex ones on a practitioner's caseload, often involving serious difficulties and competing interests, and moral and ethical dilemmas for practitioners, in trying to reconcile the service user's autonomy with the need to keep them, and their community, safe and well. This is compounded by inadequate government guidance, and wider, apparently intractable problems with multi-agency, collaborative working, which is common in self-neglect cases. It is perhaps not surprising that participant in one study of working with people who self-neglect described it as 'a foggy mass of mess' (Braye et al, 2011a, p183).

The issue of self-neglect has been framed by Rittel & Webber (1973), as a 'wicked problem'. They argue that such problems have defining characteristics, which include lack of clear definition, no definitive solution, and high levels of *behavioural* complexity. Wicked problems are,

‘characterised by deep conflicts in our assumptions, opinions, beliefs and perspectives’ (Hancock, 2010, pxiii). This very well describes the position of practitioners working with self-neglect.
The ideas of Rittel & Webber (1973) were developed by Ackoff (1974) who defined a different type of problem, the ‘messy problem’. Messy problems are those that have high levels of *system* complexity, ‘clusters of interrelated or interdependent problems’ (Hancock, 2010, pxii), whereby there are different views of the problem and contradictory solutions, and where there are likely to be ideological, political and economic constraints. It can be argued that this aptly describes multi-agency, collaborative working (Rummery, 2006).

When the wicked problem of self-neglect and the messy problem of collaborative working converge, that is, where ‘behavioural and dynamic complexity coexist and interact’, a ‘wicked mess’ may ensue (Hancock, 2010, p xiii). A recent advisory publication from the Social Care Institute for Excellence inadvertently described this wicked mess,

> Working with people who self-neglect has always been complex, requiring skilled and patient interventions. Adding it as a safeguarding category in the Care Act has opened up a new mechanism for supporting people who self-neglect… But differences of approach remain as to when and if, self-neglect should be tackled by adult safeguarding services. This is sometimes exacerbated by short-term working practices that are ill-suited to patient, ongoing work. Service providers may need to work in close partnership with other agencies to support people well (SCIE, 2017, p4).

However, as both self-neglect and collaborative working are now enshrined in legislation, it is critical that ways of tackling the ‘wicked mess’ are developed. As Head & Alford (2015) argue, ‘We contend that while conclusive “solutions” are very rare, it is possible to frame partial, provisional courses of action against wicked problems’ (p712)

Arguably, what the safeguarding statistics show (NHS Digital, 2019) is that nearly 8,000 people who were self-neglecting were helped by being dealt with under the Care Act 2014, and potential may still exist for outcomes to be improved for service users. Glasby (2017) argues that whilst the evidence may not clearly show that partnership working and integration save money, such working can improve the patient/service user experience, particularly for those with the most complex needs, and may improve the patient-centredness of services. Similarly, Goodwin (2015) argues that integrating services may support people with complex needs to live independently. Many people who self-neglect have extremely complex needs, but their overarching wish is to remain living independently. At the very least, Glasby (2017) argues that ‘even if we don’t know how well integrated care “works”, we do know that unintegrated care typically doesn’t’ (p1).

1.3 Aims of the research

Using an action research approach, this research therefore aims to build an understanding of how multi-agency working in self-neglect cases can be successfully developed, at a local level, to improve outcomes for service users. This is fully in line with an action research orientation,

> In action research there is an emphasis on a deliberate intention to intervene in a social system to bring about improvement. The result is that the research question needs to be of the type: ‘How can … be improved to improve professional practice? (Sandars & Waterman, 2005, p300)

The overall aim of this research, therefore, can be framed as the question,

- How can professionals improve the way they work together to promote the welfare of service users who self-neglect?

There are four research objectives within this;

1. What are professional’s roles and responsibilities in relation to self-neglect cases and how do the different professionals contribute to a joint understanding?
2. Do professionals share a language around self-neglect?
3. How do various professionals reach consensus in relation to self-neglect and how may different professional values conflict with each other?
4. What do professionals consider as important in achieving successful multi-agency working?

1.4 Myself as researcher

In this thesis, I write in the first person throughout. Although this has historically been avoided in academic writing, in action research it is expected (McNiff, 2017). However, McNiff (2016) argues that there are seven levels of 'I'. These are the agent 'I', the explanatory 'I', the researcher 'I', and,

> the scholarly 'I' as a reviewer of the literature, the critically reflective 'I' in relation to tentative conclusions, a dialectically critical 'I' who has a transformed perspective, and a meta-reflexive 'I' who can identify the current situation and new questions that the process has generated (O'Grady, 2018, p199).

In trying to help all of these 'I' perspectives to 'speak in harmony' (McNiff, 2016, p67), in this first person research within an action research tradition, I have interspersed reflective and reflexive 'stop-off's' throughout the text, as well as entries from the journal which I have kept throughout the research process. Such 'stop-off's' enhance the rigour of this research by their reflexive nature. As Somekh (2006) describes, I have tried to seek 'balance between personal narrative and the 'red thread' of an intellectually engaged line of argument' (p196), continually exploring and reflecting on my own positionality.

Reflexive stop-off

I am a qualified social worker. When I undertook my MSc dissertation, more than a decade ago, I carried out research in my employing local authority, where I was a social work team manager. I was fairly and squarely an insider, with the first-hand knowledge of an insider. I probably found exactly what I expected to find, because I embodied that myself. The great advantage was that it was very easy to get people to participate, because I knew many people there, and could call in many favours. I was also intensely credible. I had the same professional qualification as the people I was researching, I was one of them, and I shared their pain. I was not a detached researcher from the ivory-towered university; I was down there in the swampy lowlands getting my hands dirty. People empathised with me because I was studying as well as working, which many of them had done, and they wanted to help.

About a year after completing my MSc, I left the authority, to work for the university as a lecturer. It then happened that I was involved in an evaluation project in the authority for which I had previously worked. I was now an outsider with strong insider tendencies. I still knew everyone; I still knew the systems, the service users, my ex-colleagues, who in some cases were friends. Although the evaluation was not carried out in the team I had been in, I was still known. On reflection, I saw that I was heavily influenced by my prior knowledge and experience as an insider.

Therefore, when starting this action research, I knew that I needed to think very hard about my positionality and my own values and beliefs. I had to try very hard to be aware of, and minimise if possible, my own biases and agenda. This meant continually challenging myself, throughout the research process, to consider and reflect on what I was doing and why.

Additionally, as McNiff (2017) makes clear, because AR is always in the company of others, it is not about ‘me’ but usually about ‘we’ (p41). Returning to the idea of the wicked mess of multi-agency working with people who self-neglect, Conklin (2006) says,

> ‘You don’t so much ‘solve’ a wicked problem as you help stakeholders negotiate shared understanding and shared meaning about the problem and its possible solutions. The objective of the work is coherent action, not final solution’ (p5).

This is what ‘we’, my co-researchers and I, tried to do in this research.

1.5 Brief overview of the thesis

In Chapter 2 I explore the concept of self-neglect, its frequency and presentation, and consider what defines self-neglect, and how judgements are made by professionals about what constitutes self-neglect. I outline how self-neglect has been constructed as a social problem, and how this may have shaped the way in which people who self-neglect are viewed by professionals who work with them and by wider society. I consider critical perspectives on self-neglect, and explore the means by which interventions are permitted or denied.

In Chapter 3 I review the literature on multi-agency working. I outline my literature search strategy, following which I explore the literature on multi-agency working in adult care, in safeguarding adults, and in working with self-neglect. I discuss the role of professional judgments, particularly in relation to professional understanding of mental capacity. I then consider recurrent issues and problems with multi-agency working as identified in the literature. These include communication, lack of role understanding, power and status differences, and conflict. Finally, I explore the evidence for whether multi-agency working improves outcomes for service users, and I conclude by considering gaps in the knowledge regarding multi-agency working and self-neglect.

In Chapter 4 I set out my research methodology. My reasons for using an action research (AR) approach to explore multi-agency working and self-neglect are discussed, including an overview of the origins and development of AR and my reasons for choosing the specific model of 'professionalising action research' (Hart & Bond, 1995). I give consideration to what extent this research can be considered to be located within a participatory paradigm, and I discuss how quality can be evidenced in an AR study. I conclude the chapter with an exploration of the concepts that can be said to underpin and inform AR, and to locate it within its wider context. The influence of social constructionism and pragmatism on AR and the relationship between the three are explored.

Chapter 5 details my planning of the first stage of the AR cycle, the diagnostic or problem-sensing phase. I examine the process of conceptualising, negotiating and beginning to address the problem at the centre of my study, namely 'how can professionals change the way they work together to improve outcomes for people who self-neglect?' I then discuss reflexivity, positionality, and research ethics, before moving on to discuss the practical aspects of setting up the problem-sensing phase of the study. Negotiating entry into the client system, sampling strategy and recruitment are detailed. I then proceed to discuss the interview format that was used, and the proxemic challenges this presented me with. I continue the chapter with a discussion of my recording and transcription choices, and confidentiality considerations that I encountered. I conclude with a description of my initial data analysis considerations.

Chapter 6 presents my findings from the problem sensing phase. Firstly the initial 'Headlines' that I developed in order to feed back to the stakeholders, and to progress the AR cycle are presented and discussed. I explore data analysis considerations. A more in-depth presentation of my data from the interviews, group, individual and paired, which comprised the data for this phase, is then provided, in which I draw on combined elements of inductive, deductive and abductive analysis. My focus is on how the participants understood self-neglect, and on multi-agency working with people who self-neglect.

In Chapter 7 I describe a cycle of AR, which followed on from the problem sensing stage. I planned and carried out four multi-agency participatory workshops, in which I involved participants from all of the different agencies working with people who self-neglect. 'Action research in the moment' (Mackewn, 2009, p615) is described in relation to my facilitation of the workshops. I then discuss individual change in relation to the follow-up from the workshops, and my post-workshop reflections are provided, informed by feedback from my participants.

Chapter 8 is my discussion and synthesis of my findings from the problem sensing phase and the first action phase of my research, with the literature. It is divided into three parts. Firstly, I explore my first three research objectives, relating to role understanding, language, and consensus and conflict, in relation to the findings from the problem-sensing phase of my research, the group and individual interviews. I then consider my fourth objective, 'what works and what needs changing?' in relation to the interviews and the multi-agency workshops. I then move on to present my consideration of the overall context within which this research took place, and the impact of this on my research. I explore AR in a local and wider context, and the issue of change within an AR project such as mine.

In Chapter 9 I summarise the conclusions of my study. I considers the strengths and limitations of the study, and how I have demonstrated trustworthiness and authenticity. I describe the original contribution to knowledge that my research makes. I give recommendations for both practice and further research into multi-agency working with people who self-neglect. My reflection on undertaking this programme of research is presented, and I conclude the chapter with a brief description of further developments that have taken place in my research.

Chapter 2 – Self-neglect

2.1 Introduction

This research explores multi-agency working with people who self-neglect. It is therefore important to be clear about what is meant by the term self-neglect, and why it has become an important issue for so many practitioners. In this chapter I will outline the prevailing definitions, aetiology and frequency of self-neglect provided in the literature, and explore the construction of self-neglect as a 'social problem' (Spector & Kitsuse, 2006; Best, 2013). I will link this to the growth of consumerism, and latterly to the process of neo-liberalisation (Birch, 2015), and consider critical perspectives on self-neglect. The reification of self-neglect, whereby complex and amorphous accounts and ideas about human behaviour have been turned into a 'thing' and that 'thing' given a name (Lauder, 1999) - self-neglect – will be explored.

Self-neglect, which is now enshrined in medical diagnosis, social policy and the legal framework of the UK, has a longer research history in the USA (Braye et al, 2011a), which 'shapes how self-neglect has been researched and conceptualised' (p183), in a tradition which particularly privileges methodological precision and expert knowledge (Wacquant, 2009). Lauder (1999) notes the ways academic literature has shaped the discourse on self-neglect, and has itself to be treated with caution, being a 'somewhat incestuous and circular process in which authors cite a small number of articles, and are themselves cited in future studies … thus tentative, intuitive ideas become received wisdom' (p60).

2.2 What is self-neglect?

There is no consistent definition of self-neglect in the literature, which in itself is problematic for practitioners (Braye et al, 2013). Bates (2019) suggests there are seven components of self-neglect,

- Squalor (often including the presence of animals, vermin, faeces, etc.)
- Hoarding
- Refusal or non-compliance with medication and treatment
- Malnourishment
- Refusing help (both informal and formal)
- Poor personal hygiene
- Ignoring administration (not paying bills or opening mail).

Snowdon & Halliday (2012) subdivide squalor into 6 categories. These range from 'dry clutter' (disorganisation rather than neglect) to 'wet, neglectful squalor' (p12). In the latter,

> The home may be filthy, but [as well as] a large quantity of rubbish, there is excrement (animal or human faeces, urine and maybe vomit) throughout the dwelling, especially around the toilet bowl or in other places where humans excrete. Neglected overflow or spillage, and rotting food may accord with the descriptor of 'wet squalor' (ibid).

Animal hoarding, also known as 'Noah Syndrome' (Saldarriaga-Cantillo & Nieto, 2014) is defined as the 'accumulation of animals (20 or more) that are not intended for breeding or sale' (p348). Braye et al (2014a) follow a common division in the literature and distinguish between cases of failure to care for self and failure to care for surroundings, and argue that typically one or the other is dominant. As McDermott (2011) notes, in the USA the term 'self-neglect' refers to both neglect of the person and neglect of the environment, whereas in Australia neglect of the person (self-neglect) is separated out from squalor (environmental neglect). These are important distinctions for practitioners dealing with self-neglect, as it is likely to be the cases of severe domestic squalor that may perhaps be the most intractable and require the best co-ordinated and creative response from services. For example, Frost et al (2000) found that people who hoarded animals (frequently dead) presented significantly more difficulty to external agencies, than those who only hoarded possessions, in terms of levels of insanitary conditions and multiple involvements of agencies. Similarly, there is often a distinction made between intentional and unintentional self-neglect (Dyer et al, 2005).

Lauder et al (2001) shifts the definition of self-neglect by adopting a constructionist perspective, and defines self-neglect as ‘the failure to engage in those activities which a given culture deems necessary to maintain a socially accepted standard of personal hygiene and household hygiene and carry out activities needed to maintain health status’ (p601). Whilst it is perhaps easy, on a day-to-day basis, for practitioners to get caught up in concerns about the physical manifestations of self-neglect, Lauder makes a crucial point here, which, as will be demonstrated later, impacts upon the responses of practitioners working in this area and the wider public perception of those who reject the ‘hygiene consensus’ (Lauder et al, 2005a, p47).

Reflective stop off
Amongst the many different definitions of self-neglect is one from Dyer et al (2007, p1671) who write that ‘Self-neglect is the inability to provide for oneself the goods or services to meet basic needs’. This is surely a definition of poverty rather than self-neglect?

2.2.1 What is the frequency of self-neglect?

There is wide variation in estimates of frequency of self-neglect in the general population. Some studies report that self-neglect is a factor in about 20% of cases known to mental health and older people’s services (May-Chahal & Antrobus 2012; Day et al, 2012). In the USA all but 15 states have mandatory reporting of self-neglect (Dyer et al, 2007) and Lauder et al (2005a) posit that if the US data were extrapolated to the UK, there would be 27,000 to 28,000 cases per year. Additionally, they note that a project in the USA in 1998 concluded that for every substantiated case there might be five other cases that are not known to agencies, referred to as ‘the iceberg effect of self-neglect’ (Lauder, 2005a, p46). Sherman (2008) writing about prevalence in the US, states that ‘Self-neglect is the most serious problem confronting Adult Protective Services agencies, throughout our nation, accounting for almost one half of all referrals’ (p9). Dyer et al

(2007) echo this, stating that ‘in almost every US jurisdiction, it is the most common problem faced by Adult Protective Services’ (p1671). They quote a range of prevalence studies with figures ranging from 70% in one study to 62% in another. Respondents in O’Brien et al’s 2014 study of Irish GP’s found that they reported psychological abuse and self-neglect as the most common types of abuse they encountered and the most difficult to manage.

Research documenting the prevalence of hoarding is also limited. An epidemiological study by Samuels et al (2008) reported prevalence figures ranging from 2.3% for ages 33–44 to 6.2% for ages 55–94, though comparing a range of 11 years with a range of 39 years does weaken these figures. Barnett (2015), extrapolating from other studies, finds a prevalence of hoarding from 2.3% to 6%. However, Nordsletten et al (2013) write that the prevalence of hoarding is over-estimated. Their study, which took place in south East London, found prevalence of the disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013), to be 1.5% of the population. Preston-Shoot (2018) in his analysis of Safeguarding Adult Reviews (SARs), seems to concur with this, as he found that both refusal of services and lack of self-care were considerably more prominent as reasons for a SAR being commissioned (i.e. the central feature of the case) than lack of care of one’s environment.

The Care Act 2014 has enabled some more precision, though limited to a particular area of self-neglect. Safeguarding statistics for England and Wales are collected annually by local authorities, and it is now mandatory for them to report on the numbers of concluded Section 42 safeguarding enquiries they have carried out. During 2017/18, it was reported that 6,435 Section 42 enquiries were concluded for self-neglect cases (NHS Digital, 2018). It must be remembered that these are the highest risk, most complex cases, which are deemed to reach the threshold for a S42 safeguarding enquiry[1], so are not representative of the general population. There will also be many other cases which do not meet this threshold, and hence do not appear in the figures, but require a response from local authorities and others. It is also worth noting that in the space of four years of implementation of the Care Act 2014, self-neglect cases have gone from nil to their current levels, which now equal, for example, the numbers of organisational abuse cases dealt with by local authorities. However, it is not possible to know from these figures what form the self-neglect took, or the prevalence of hoarding as a distinct issue. Additionally, no demographic information is collected which might inform work in this area.

2.2.2 The causes of self-neglect

The dominant ontological perspective in research on self-neglect is the medical model (Lauder et al, 2005a; Orr et al, 2017), where self-neglect, and particularly hoarding, is seen as an illness or biological disfunction. However, such a perspective has not been notably successful in providing consensus on either the cause of, or the most effective resolutions to, problems presented by self-neglect. There is little agreement on the causes of self-neglect, and various explanations are sought within the literature, sometimes with a desire that can seem almost desperate. One study suggests for example, that 'hoarding severity was negatively correlated with glucose metabolism in the dorsal anterior cingulate gyrus' (Lopez Gaston et al, 2009, p348), which may be true, but is of little help in understanding self-neglect. In fact, McDermott (2010) argues that there is still a widespread belief that biological disfunction can be held entirely responsible for self-neglect.

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[1] *Care Act 2014, S42* **Enquiry by local authority**

(1) This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there)—

(a) has needs for care and support (whether or not the authority is meeting any of those needs),

(b) is experiencing, or is at risk of, abuse or neglect, and

(c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

(2) The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in the adult's case (whether under this Part or otherwise) and, if so, what and by whom.

In several studies (Swanson & Smith, 2011; Emmanouil-Stamos et al, 2012), self-neglect is seen as a psycho-medical condition, in some cases a psychiatric syndrome, which may be associated with other accompanying mental disorders. These may include dementia, cognitive impairment, frontal lobe dysfunction and depression (Lauder et al, 2005a). Around half of people who self-neglect are thought to have underlying mental and physical disorders (Abrams et al, 2002). The corollary of this is that half do not (Lauder et al, 2005a),

> It would seem that the presence of a mental illness should not necessarily be presumed to be causally related to self-neglect. Any such link may be more complex than a simple linear cause-effect relationship, as may be implied in the disease model (Lauder, 1999a, p55).

Lauder et al (2005a) found however, that having a psychiatric diagnosis acted as a perverse incentive in that it was key in opening up access to resources for the self-neglecting person. This raises the issue of resources and support which may be denied those who do not have a 'diagnosis' such as Hoarding Disorder (discussed further below), or who are deemed to have capacity to choose to self-neglect, within the definitions of the Mental Capacity Act 2005. One American study (Aamodt et al, 2015) found that of clients referred to American Protective Services for capacity assessments, those living in squalor were no more cognitively impaired than those not living in squalor. In fact, those living in squalor demonstrated better memory and general performance. Payne & Gainey (2005) in the US, found that college graduates were more likely to be diagnosed with self-neglect than those with fewer qualifications.

Other studies locate self-neglect within a socio-cultural paradigm, 'which at its extreme sees self-neglect as a social construct influenced by social, cultural and professional values, in effect a perceptual judgement as opposed to an objective phenomenon' (Braye et al, 2011a, p184). Bozinovski, (2000, p52), unambiguously writes that 'Self-neglect is not an objective, measurable entity or process. Rather, self-neglect is a complex, ambiguous, multifaceted social construction'. Lauder et al (2001) contend that,

> Self-neglect can be understood as the failure to engage in those activities which a given culture deems necessary to maintain a socially accepted standard of personal and household hygiene and carry out activities needed to maintain health status (p601).

Lauder et al (2005a) also argue that self-neglect is seen as a violation of accepted social norms and standards and people who do not conform to these are at risk of being labelled 'diseased and disordered' (p47). Douglas (2002) states,

> Dirt is essentially disorder. There is no such thing as absolute dirt: it exists in the eye of the beholder… in chasing dirt we are positively re-ordering our environment, making it conform to an idea (p2).

The beholder here, bent on re-ordering and conformity, is often the social care, health or housing professional.

Braye et al (2011a, p186) suggest that alongside this social constructionist approach sit social psychological models, 'that consider the interplay of factors external and internal to the individual' (for example, Chapin et al, 2010). A study by Burnett et al (2006) found strong evidence for an association between decreased social resources and networks, depression, and self-neglect.

Studies that have been carried out with self-neglecters generally aim to understand *why* people should behave in this way. Reasons identified include: pride in self-sufficiency, a sense of connectedness to place and possessions, and behaviour that attempts to preserve the continuity of identity and control (Bozinovski, 2000; Lauder et al, 2009; Braye et al, 2011b; Orr et al, 2017). Bozinovski's (2000) study of older self-neglecters identified factors such as relationship failures, abandonment, betrayals and relationship regrets, and discusses 'turning points' in people's lives which appear to precipitate self-neglect. Amongst participants who neglected their environments, Braye et al (2014a, p103) found four themes identified - 'influence of the past', 'positive value of hoarding', 'reasons beyond interviewees' control' and 'uncertainty about reasons'. However, what many of these participants seem to be referring to is 'hoarding', which is the 'purposeful collection of items' (Snowdon et al, 2007), rather than severe domestic squalor.

Brown (2011) argues that decisions about self-neglect are affected by history and memories, particularly at times of stress, vulnerability and loss. Lien et al (2016) identify that traumatic experiences are often part of people's journey to self-neglect, and this may have a link to adverse and traumatic childhood events, and childhood attachment styles (Bowlby, 1969). These continue into adulthood, particularly in relation to hoarding. Orr et al's study (2017) observes how adult attitudes to possessions can be shaped by childhood deprivation. The findings from a study by Medard & Kellett, (2014) into the link between attachment and hoarding indicate that 'the more hoarders have disturbed relationships with people, the more disturbed their relationships with possessions' (p633). Barnett (2015) describes how hoarding can be thought of as the person's best attempts to meet their own attachment needs for comfort, safety, proximity and predictability, and Lopez Gaston et al (2009) suggest that the person's intentions for, and attachment to, the objects that are hoarded are key factors in a diagnosis of hoarding. Tellingly, both Johnson & Adams (1996) and Buckingham et al (2008) found that practitioners often did not consider past history or biography when supporting self-neglecting people.

Closely related to attachment, there also appear to be links with loss and bereavement, going back to Macmillan & Shaw's 1966 study, which found that the precipitating factor for deterioration was very often bereavement and the subsequent grief experienced. Lopez Gaston et al (2009) note that for the person who hoards, to dispose of their belongings induces grief-like emotions. Thus in relation to attachment and loss, objects come to represent emotions way beyond their physical reality. Picking up on Burnett et al's (2006) finding of decreased social networks amongst self-neglecters, it also appears that loneliness is an important linked factor. Lopez Gaston et al, (2009) note studies which show a low rate of marriage among people who hoard, and that their symptoms of self-neglect may make it harder for them for sustain relationships, and that a high proportion of people who self-neglect live alone.

2.2.3 How can we judge if people are self-neglecting?

A bewildering, highly medicalised, plethora of tests and scales are suggested by different authors to assist the assessment or measurement of the extent of self-neglect (Naik et al, 2006; Snowdon & Halliday, 2012; Iris et al, 2014; Abrams et al, 2018). These measure factors such as severity of self-neglect (Dyer et al, 2006); obsessive-compulsive symptoms; and the activities of daily living, as well as tests of cognitive ability/capacity (Aamodt et al, 2015). Such tools tend to come from the USA (e.g. the ESN scale (Iris et al, 2010)), so may not be directly relevant to the UK situation. They also tend to focus exclusively on older people (Abrams et al, 2018).

In a US study by Dyer et al (2007) of 538 'instances of self-neglect', participants who had been identified by professionals as self-neglecting were subjected to what are described as a 'battery of geriatric assessment measures' (p1672). These included:

- Mini Mental State Examination (cognition)
- Geriatric Depression Scale (depression)
- The physical performance test (activities of daily living)
- The clock drawing test (executive function)
- The Functional Activities questionnaire (activities of daily living)
- The self-health questionnaire, (physical health and nutrition)
- The Duke Social Support Index (social support)
- The Cut-Annoyed-Guilt-Eye Opener (CAGE) questionnaire (alcohol use) (ibid)

Sherman (2008) develops the Bill Paying Performance Test. Wheaton (2016) offers, for measuring hoarding, the Stockings of Cambridge task; the Tower of London task (both to measure planning ability); and the Iowa Gambling Task (a measure of decision making for monetary gain). He notes that 'it has been suggested that gambling tasks do not adequately probe the facets of decision making that are impaired in hoarding' (p45). In fact, it is hard to see any connection at all between gambling and hoarding.

It is questionable how useful these tests are, and Gunstone (2003) identifies resistance to the use of objective assessment tools, in many cases because of their strong medical model bias. Chan et al (2016) argue that using such tests and relying too heavily on the identification of risk factors is in itself dangerous and may be falsely reassuring. There are currently no tools in widespread use amongst multi-disciplinary teams in the UK to identify and define self-neglect of the person.

There are also various tools available to measure neglect of the person's environment, though as Snowdon & Halliday (2012, p103) note, these are largely untested in terms of reliability and validity, and there is no 'gold standard' tool. Tools include those freely available on the internet, aimed at the 'worried untidy' which typically offer quizzes for self-diagnosis. There are also tools available for professionals, for example Research in Practice for Adults (RiPFA, 2015) has recently issued a 'practice tool' for adult social care, though this is not nationally or freely available, and is aimed only at social workers (whilst, ironically, stressing the importance of multi-disciplinary working). Since the inclusion of self-neglect into the Care Act, there has been widespread adoption by local authorities, despite its very weak evidence base (Herring, 2014), of the 'Clutter Image Rating' (Frost et al, 2007, see Appendix 1), a series of photos of rooms found in most houses (e.g. kitchen and living room), which are progressively filled with clutter. However, the UK is still some way from having a national, validated tool.

2.3 The construction of self-neglect and hoarding as a social problem

It is argued that social problems have a 'natural history' (Spector & Kitsuse, 2006; Best, 2013) that is, a multi-stage process by which problems emerge, and this process can be applied to self-neglect (see Table 1, below). This starts with 'claims-making' (Schirmer & Michailakis, 2016) by a given group, claims which are framed and communicated as social problems, until eventually they become formulated into legislation, or cease to be of public interest. Schirmer & Michailakis describe the function of claims makers as being to ‘construct particular (putative) social conditions as problematic, violating widely shared values, harming particular groups of people and in need of remedy’ (p5). A topic must be brought to public attention as a ‘troubling condition’ (Best, 2013, p15) that needs to be addressed. Claims may be made by various ‘claims-makers’. In the case of self-neglect, those claims largely came from medical experts (who, according to Best (2013) are an accepted category of claims-maker, in the eyes of the public). These set the tone of the subsequent problem development over the following decades, inadvertently described by Johnson & Adams (1996), 'It is through such authoritative literature that self-neglect has become established as a clinical syndrome' (p229).

Table 1: Natural History Model of the Social Problems Process applied to self-neglect and hoarding (Adapted from Best, 2013, p19).

‘Claimsmaking’	Media Coverage	Public Reaction	Policymaking	Social Problems Work	Policy Outcomes
People make claims that there is a social problem, with certain characteristics, causes and solutions	*Media report on claims-makers so that new of the claims reaches a broader audience*	*Public opinion focuses on the social problem identified by the claims-makers*	*Lawmakers and others with the power to set policies create new ways to address the problem*	*Agencies implement the new policies, including calls for further changes*	*There are various responses to the new arrangements*
1940’s USA, ‘Collyer Brothers Syndrome’ is identified (Herring, 2014) Macmillan & Shaw (1966) identified ‘senile breakdown’ Clarke et al (1975) identify ‘Diogenes Syndrome’ Frost & Gross (1993) claim that hoarding is common.	TV programmes: A Life of Grime (1999) Hoarding: Buried Alive (2010-2014) Britain’s Biggest Hoarders (2012 onwards) The Hoarder Next Door (2012-14) Obsessive Compulsive Hoarder (2011) Newspaper coverage: ‘Inside Merseyside’s stomach churning homes from hell’ (Liverpool Echo headline, 8 Nov 2016) He said, “We have young people who hoard and old people who hoard. It’s a mental issue”. (Liverpool Echo, Nov, 2016)	‘Disgusting images offer a glimpse into a self-confessed hoarder’s disgusting flat – before cleaning specialists gave it an extreme makeover’. (Metro 23 Jun 2017) Rise of the professional de-clutterer (Herring, 2014) Publication of self-help books, e.g.: *The Life Changing Magic of Tidying Up* (Kwondo, 2011); *The Gentle Art of Swedish Death Cleaning* (Magnusson, 2017); *A Monk’s Guide to a Clean House and Mind* (Matsumoto, 2018)	National Assistance Act 1947 Human Rights Act Mental Capacity Act 2005 Care Act 2014 – inclusion of self-neglect as a statutory issue Inclusion of ‘Hoarding Disorder’ as a new psychiatric diagnosis in the DSM5 (used in the USA and the UK)	2016 - Action on Elder Abuse calls for more powers to enter the homes of vulnerable people. 2017 – Liverpool Coroner asks Home Secretary for change in the law so Fire Services have the right to enter people’s homes 2016 & 2017: Figures show huge increase in self-neglect cases	Emerging questions: Are policies effective? Do they go far enough? How do we deal with complex cases? How far should we interfere in people’s lives? Measurement is incomplete and ambivalent

Subsequent stages of the claims-making process (see Table 1) are:

- Media coverage - which encourages the population to feel outrage or compassion. For example, Orr et al (2017, p2) describe how hoarding has gained an increasingly high profile in recent years ‘as popular television shows and books have moulded popular perceptions of individuals whose accumulation of possessions is judged to be excessive’.

- Public reaction – For example, Best (2013) discusses how the telling of ‘urban legends’ and jokes are important parts of shaping the public reaction.

- Policymaking - This is encapsulated neatly in the ‘troublesome’ issue of self-neglect which has undergone a process of reification over the last decade or so, become a ‘thing’ that is now enshrined in safeguarding legislation in the Care Act 2014, and tempered and defined by the Mental Capacity Act 2005. Habermas (1987) describes this as the process of ‘juridification’ – an ‘increase in formal or written law … an expansion of law of hitherto unregulated conduct’ (p359).

- ‘Social problems work’ - all of the agencies in this study are at the stage of doing the ‘social problems work’ as described by Best (2013), dealing with the day to day issues associated with self-neglect. Whilst claims-makers, the media, the public and policy makers are all able to discuss social issues in fairly abstract terms, ‘social problems workers … must deal with particular cases and address a messy real world’ (p22).

- Policy outcomes –currently, policy outcomes in relation to self-neglect are unclear, although according to Penhale et al (2017), there does appear to be some ambivalence towards including self-neglect as part of safeguarding, after initial enthusiasm. She suggests there is continuing uneasiness with the State having powers of intervention and that the Care Act was a compromise based on competing perspectives.

Reflective Stop-Off

It is very interesting to reflect on how the construction of self-neglect and hoarding as a problem has an impact on participants in this study, particularly in relation to the 'public reaction' stage discussed above. Naturally, as members of society, the participants are subject to all of the media attention, the television programmes, the self-help books with their hyperbolic 'linking of material and mental cluttering' (Löfgren, 2017, p4) that the wider community are. But unlike members of the wider community, who may never encounter an actual self-neglecting person, they are working with them all the time. In the group interviews I ran, I was party to many informal conversations, often before the groups started, where participants (predominantly female) talked and joked about the clutter in their own homes, wondered aloud if they (or their spouses) were hoarders, talked about having a 'de-clutter'. They would talk about the TV programmes about hoarders that they watched, often admitting that they loved the programmes, even whilst acknowledging it was a form of guilty voyeurism.

I found it fascinating that they worked with people who self-neglected, then went home and watched programmes about them. They were part of the discourse of cleanliness and tidiness, in which people who are excessively dirty are to be seen as disordered and unhealthy (Lauder, 1999a) yet is was their job to work in a non-judgemental way with those people. I also noticed how willing participants were to talk about the more bizarre examples of client's behaviours, and often these were told as funny stories. Some stories have a sense of 'urban' or 'contemporary' legends, as described by Best (2013), and in one case, I heard the same service user/patient's (admittedly bizarre) behaviour described independently by three different sets of practitioners who were all working with him.

2.3.1 The construction of a mental illness

Early studies into self-neglect (Macmillan & Shaw, 1966; Clarke et al, 1975) provided scant evidence that self-neglect was a psychiatric syndrome (Johnson & Adams, 1995), and in themselves served to reinforce stereotypical ageist and gender based assumptions. Nonetheless they made claims that were significant in establishing the self-neglect and hoarding discourse.

Macmillan & Shaw in 1966, in their article '*Senile Breakdown in Standards of Personal and Environmental Cleanliness'* presented a vivid picture of what 'the *condition* (my italics) senile breakdown' meant:

> The usual picture is that of an old woman living alone, though men and married couples suffering from the condition are also found. She, her garments, her possessions, and her house are filthy. She may be verminous and there may be faeces and pools of urine on the floor. (p1032)

Their study involved 72 hospital patients (12 men and 60 women) whom they graded according to 'their adaptations to the social conventions' (p1032). This was not a 'passive deterioration' either they noted, as might be expected of older people, it was a 'hostile attitude to the outside world' (p1036). Clearly, these were not people who deserved much sympathy, because,

> The pattern which emerged again and again was that of a domineering, quarrelsome and independent individual. Typical of the adjectives applied to them were independent, unfriendly, stubborn, obstinate, aloof, aggressive, suspicious, secretive and quarrelsome. (p1034).

They were violating shared values (Schirmer & Michailakis, (2016) and in need of remedy. However, the authors were unable to usefully state what the remedy might be, except that early intervention could help. They placed the responsibility for this on 'the family doctor and community workers'. There was also, however, a legal remedy. Section 47 of the National Assistance Act 1948 allowed for the removal from their homes of a person who was,

> suffering from grave chronic disease or, being aged, infirm or physically incapacitated is living in unsanitary conditions; and the person is unable to devote to himself, and is not receiving from other persons, proper care; and his removal from home is necessary, either in his own interests or for presenting injury to the health of, or a serious nuisance to, other people. (NAA, 1948, S47).

In effect, a person could be removed from their home if they were old and annoyed their neighbours. This legislation was not repealed until the introduction of the Care Act in 2015.

In 1975, Clarke, a geriatric physician, in a further attempt to medicalise self-neglect (Ungvari & Hantz, 1991) wrote an influential article in which he gave 'senile breakdown' a different name - '*The Diogenes Syndrome'.* Moore (1989) notes comparison with Diogenes is inaccurate, as he was reputed to be intrinsically happy, self-sufficient without material wealth, and enjoyed company. The person with Diogenes Syndrome, according to Clarke, was none of these things, but was instead ‘aloof, detached, shrewd, suspicious, aggressive and emotionally unstable, serious minded and tending to distort reality’ (Clarke, 1975, p801), (and usually, as Lauder et al, (2005a) note, an older person). There will be ‘purposeless hoarding of useless rubbish’ for which the person ‘seldom expresses shame or apology’ (Clarke, 1975, p801). There is a clear implication that these people are deviant in that they do not behave in a particular way that should be expected of someone in their situation, that they should be apologetic and ashamed. Nevertheless, Clarke does begin to wrestle with some of the dilemmas which are still very pertinent today – have we the right to ‘force them to conform to normal accepted social standards’? (p802). Is it right for the person ‘to enjoy freedom in filthy domesticity or have forced upon them the healthy cleanliness of a welfare home?’ (ibid).

Clarke’s definition of Diogenes Syndrome has been paradigmatic, an ‘iconic term’ (Lopez Gaston et al, 2009, p344) but with, they argue, limited clinical use. Muir-Gray (1988) sees the term more as a reflection of the ‘desire of the medical profession to classify individuals than of the objective existence of any condition’ (p211). However, Dyer et al (2007) describe how the term expanded to describe younger people with mental illness, people with personality disorders and persons without identifiable diagnoses, and there were suggestions that it should include a distinction between primary and secondary Diogenes syndrome ‘depending on whether a mental disorder is present’ (Lopez Gaston et al, 2009, p344).

Reflective stop off

It was very interesting during the course of my fieldwork, to hear how often the term ‘Diogenes Syndrome was still used (and misused) by practitioners. One person stated how she had tried to describe it to someone during an argument, by explaining; ‘it’s Diogenes disease, it’s a disease’.

2.3.2 Enter Hoarding Disorder

In 2013, hoarding reached its apotheosis in terms of claims making when the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013) 'introduced a new mental disorder' (Barnett, 2015). Hoarding Disorder (APA, 2013, p247), is described as 'a persistent difficulty discarding or parting with possessions'. This had been 'fissioned off' (Orr et al, 2017, p1) from the diagnosis of Obsessive-Compulsive Disorder, to become a new diagnosis in its own right. Here was a disorder, which, usefully, according to the Royal College of Psychiatrists, could 'be diagnosed when there is no other illness to account for the problem' (RCP Hoarding advice leaflet, 2016, p2). The RCP are in no doubt that hoarding is 'dangerous in a number of ways', one being that 'Piles of possessions can collapse and crush you – perhaps even kill you' (p3). Although Orr et al (2017, p2) argue that a diagnosis of hoarding disorder may bring welcome consequences, such as forestalling an eviction, they also acknowledge concerns about 'psychiatric over-reach and the pathologisation of unremarkable human experiences' (p2) and the potential for the delegitimising of individuals' own perspectives on the 'problem'. This would seem to be a perfect example of Foucault's point (1978) that psychiatry functions as 'a sort of public hygiene' (p6) in that psychiatrists can diagnose hoarding disorder, which will enable to them to clean up individuals and their dwellings on behalf of wider society, regardless of the desire of the person themselves. Foucault also discussed the symbiotic relationship between psychiatry and the penal system (1978) in relation to what he termed the 'dangerous individual'. This the hoarder most certainly is. As the RCP remind us 'severe hoarding can be a risk to others as well as to yourself' (RCP, 2016, p3). As such, a psychiatric diagnosis can sanction penal and penalising interventions.

Hoarding disorder has quickly entered the professional discourse and the public imagination, particularly with the parallel development of television shows and books (Herring, 2014; Orr et al, 2017).

Reflective stop-off
This was directly demonstrated to me in the following exchange. At a conference, after listening to a presentation on hoarding disorder, the person next to me, who worked in Housing, reflected happily, ‘so if I can get them diagnosed with hoarding disorder, I can go in and do a clear-out? Result!’

2.3.3 Deviant neoliberal citizens

Steger & Roy (2010, p12) suggest that neoliberalism ‘puts the production and exchange of material goods at the heart of the human experience’. For Massey (2013) this means that it is a person’s ‘prime duty (and source of power and pleasure) to make [consumer] choices’ (p10). Löfgren (2017), in his discussion of mess as ‘the overflow of domestic consumption’ (p5) argues that the market plays a double role in encouraging the flow of commodities into the home, then assisting in the divestment of these commodities (de-cluttering, storage solutions, etc.). However, people who self-neglect and hoard transgress these consumerist norms (Herring, 2014; Orr et al, 2017), and thus do not fulfil their duty as citizens (Massey, 2013). They may have a flow of commodities into their homes, but these are usually the discarded commodities of others, and they do not divest themselves of these commodities as we might expect, but guard them fiercely. They have rejected the ‘attainment of the perfect self’ (Eagleton-Pierce, 2016, p104) through the purchase of commodities. Further, they have often rejected the attainment of the perfect physical self, rejected the role of useful citizen or beloved relative, and are instead people whose ‘eccentricity of behaviour was found to frighten neighbours who might otherwise have helped’ (Macmillan & Shaw, 1966, p 1034). They are Cohen’s (2002) ‘folk devils’ who cause ‘moral panic’ and represent a ‘threat to societal values and interests’ (p9).

However, in another sense, people who self-neglect are the perfect neo-liberal citizens. Ferguson (2008) argues that we live in a world of ‘responsibilisation’, that is, ‘a world where many things are up to you’ (RiPFA, 2015) whereby we are exhorted to take responsibility for ourselves and our families and not rely on State support. Self-care, the very opposite of self-neglect, is described as being ‘about individuals, families and communities taking responsibility for their own physical and mental health and wellbeing’ (Skills for Care, 2017), particularly in relation to health and social care. As Clarke (2005) has noted, the new ideal citizen is one who wants to ‘decide for themselves’ (p450) rather than expecting the government to provide for them.

Many people who self-neglect make decisions about their own health in that they refuse to engage with treatment plans, medication regimes, etc. They may refuse to use social care services. They therefore relieve the pressure on the system by non-participation. However, this cannot be seen as self-improvement, a requirement of citizenship (Jordan, 2004; Singh & Cowden, 2015), and in their vulnerability, self-neglecters are problematic, even dangerous individuals (Foucault et al, 1978) who threaten the social order. They are, in neoliberal terms, dysfunctional people (Singh & Cowden, 2015), who must be controlled on the one hand, whilst being encouraged to be autonomous and empowered on the other.

2.3.4 A lifestyle choice? The toxic euphemism of self-neglect

Self-neglecting individuals, living in circumstances which may evoke pity and disbelief in the wider population and a cry of ‘why isn’t something being done?’ thus pose a challenge to **‘**the self-improving mission of neo-liberal governmentality’ (Singh & Cowden, 2015, p378). One way to minimise that challenge is to suggest that living in this way, (perhaps unwashed, unfed, cold, dirty) is a deliberate choice for these people, indeed a ‘lifestyle choice’, and this is a phrase often encountered in the literature and in practice (Mayes, 2015). The idea of lifestyle, which originates from the work of psychoanalyst Alfred Adler (Featherstone, 2015) can be defined as ‘leading life in sympathy with a plan, principle or ethic’ (p383), and is now generally used to mean a person’s approach to life, particularly through their choices of consumption. Simmons & O’Brien (2000) argue that our lifestyle choices express ‘ground-of-meaning beliefs by which one defines the self and the purposes that give meaning to life' (Simmons & O'Brien, 2000), and that 'personal habits that others perceive as self-neglect may be entirely consistent with the pursuit of values important to the person.'(p39).

According to Scourfield (2010) however, 'Most people do not, at some clear point in their lives, choose to live in squalor and danger' (p24). He suggests that many self-neglecting people have simply adapted to conditions that have got worse over time, and that many conditions come about by default, not as the result of a rational decision making process. Such 'choices' are 'not necessarily undertaken with the calculated aim of leading a particular lifestyle as if it was the result of a grand plan decided upon earlier in life' (p24). He suggests that people are 'clinging' to a certain lifestyle rather than making a conscious 'lifestyle choice' (p29). Arguing that something is a 'lifestyle choice' may simply be a convenient way to permit non-intervention. 'Lifestyle', a term linked to healthism and wholesome living, has been hijacked, argues Mayes (2015), drawing on the ideas of Foucault, to support discussions of obesity and unhealthy lifestyles, and these can equally well be applied to self-neglect. By calling self-neglect a 'lifestyle choice' it allows policy makers, argues Mayes, to 'justify narrowing the circle of collective welfare in a manner that excludes those that are perceived to choose irresponsibly' (p5). These people are then able to be excluded from the 'secured population' (p6), because they have chosen to live in this way.

2.3.5 Service refusal as a manifestation of self-neglect

In the Care and Support statutory guidance for practitioners (2014, p234) which accompanies the Care Act 2014 it is stated that self-neglect 'covers a wide range of behaviour such as neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding'. However, a subsequent 'Leaders Briefing' from RiPFA shifts the emphasis slightly, describing self-neglect as including 'neglect of self-care and/or one's environment, often involving refusal of services' (Preston-Shoot, 2015, p5). However, as a general principle, anyone is entitled to refuse services, unless legally mandated otherwise, for as John Stuart Mill (1859/2006, p) wrote, 'Over himself, over his own body and mind, the individual is sovereign'. Yet here, service refusal has become something that is a problem in itself. Skills for Care, a key organisation for the training of adult care staff takes this further in its tripartite definition:

> 'There are three main forms of self-neglect:
>
> - Lack of self-care - this includes neglect of someone's personal hygiene, nutrition and hydration, or health, to an extent that may endanger safety or well-being.
> - Lack of care of a person's environment - this includes situations that may lead to domestic squalor or increased risk in the domestic environment.
> - Refusal of services - this might include refusal of care services in either their home or a care environment or of health assessments or interventions, even if previously agreed'. (SfC, 2015)

Refusal of services has become here a 'form' of self-neglect, and a disruption of the long established principle of *voluntas aegroti suprema lex*, the right of the patient to choose to accept or refuse medical treatment, here extending to other forms of treatment or service. It is implied above that the seemingly capricious and unreasonable act of refusing services *'*even if previously agreed' or if they could *'*potentially improve' things compounds the problem. A comment from Lauder is apposite here – 'the language used conveys a sense of moral judgement as much as it describes a clinical symptom' (Lauder 1999, p59). Hurst (2004) describes a circular line of reasoning, whereby if a self-neglecter refuses to provide a satisfactory reason for refusing beneficial treatment, the refusal is taken as evidence of the absence of decision-making capacity, and treatment can then be provided.

Research on those who self-neglect has generally reported a strong reluctance to co-operate with health and social care staff (Lauder, 2005a, p50). It has also reported perceptions that they are victims of intrusive enquiries and service delivery by investigators and health and welfare professionals, and unwillingness to co-operate in the process of service delivery (ibid). Muir-Gray (1988) writes that self-neglect in itself is not the problem. The problem is when people refuse help. However, this view pathologises the individual, when it is perhaps more likely now that inability to obtain help rather than refusing help is the more pertinent contributor to self-neglect. Given the extent of cuts to local authority services in recent years, it is now the case that nearly 1.2 million people over the age of 65 (1,183,900) do not receive the help they need with essential activities. This means nearly 1 in 8 older people now live with some level of unmet need with vital everyday tasks (Age UK, 2018, p12). There is therefore another line of reasoning. If a person is denied services because they do not meet the eligibility criteria for example, they may be more likely to be unable to care for their person, perhaps because they are incontinent and cannot access the toilet, or struggle to wash themselves. This can then be construed as self-neglect.

2.4 Critical perspectives on self-neglect

It is argued that the neoliberal project, with its expression of relentless optimism about individual capacity to overcome adversity and to make positive choices, fails to acknowledge structural inequalities, when there is 'ample evidence that social factors shape every aspect of the human malaise' (Gray, 2011, p9). Ash (2014, p15) argues that this 'microfication', or attention to individual categories and characteristics means we fail to 'see' the macro-level issues in a situation like self-neglect, such as the impact of structural factors like ageism and poverty and inequality, and cultural norms and values. What is particularly of concern here is that practitioners may see vulnerability as a psychological characteristic rather than the result of factors such as poverty (Chandler & Reid, 2016) and social exclusion.

2.4.1 The influence of social class and the nature of eccentricity

A concept that is often used to describe the behaviours of some people who self-neglect and hoard is eccentricity (Simmons & O'Brien, 2000), and there seems to be a fine line between them. In British culture there is a tradition, from Miss Havisham in Charles Dickens 'Great Expectations' to Alan Bennett's 'Lady in the Van', of eccentric, clearly upper class, 'characters'. Weeks & James (1995) in their study of eccentricity, argue that in the UK there was traditionally a high toleration of bizarre and eccentric behaviour from the upper classes, who were 'warmly regarded' (p37) by the general populace. Even today we can see remnants of this regard, or at least acceptance of the old social order, in the Channel 4 television programme, '*Obsessive Compulsive Country House Cleaners'*, which effectively re-creates the servant/master paradigm, except in this case the 'servants' all have a diagnosis of obsessive compulsive disorder, and the 'masters' live in filthy, decaying, but nonetheless extremely valuable properties, which the 'servants' will clean for them during the programme.

Löfgren (2017, p4) argues that 'Intellectual bohemians' have always been granted greater leeway, for though their domestic disorder might be problematic, it was also creative. Not so 'the lower strata of society', writes Fottrell, (1988, p10) who concludes that living in squalor as older people should not be viewed as exceptional where such people have lived their lives in these circumstances. In relation to the way that hoarders are now portrayed on television, 'most of the hoarders we see on TV are working class people, and they don't appear to be working' (Acocella, 2014, p61), inviting both our disgust and condemnation. They are clearly, as Mayes (2015) describes, 'excluded from the secured population' (p6). Even in the world of self-neglect it seems, class, and money, talk.

2.4.2 The representation of older people in the self-neglect story

Critical gerontology argues that older people have long been marginalised and ignored, and that it is important to consider our beliefs about older age and how, as individuals and as a society, we respond to older people (Ray et al, 2009). As de Beauvoir (1972) wrote, 'Old age in others causes an instant repulsion. The immediate, natural attitude is to reject it, in so far as it is summed up by the words decrepitude, ugliness and ill-health' (p25).

Many studies on self-neglect focus specifically on older people, though the hypothesis that self-neglect is more prevalent in later life is poorly evidenced (Johnson & Adams, 1996, p229). Lopez Gaston et al (2009, p345) point out many studies on hoarding have relied on data based on referrals to specialist health services, which biases the data towards certain groups, such as older people. As previously mentioned, the government in England and Wales has decided against publishing demographic information about referrals to services for people who self-neglect, so it is impossible to get an accurate picture of its prevalence amongst older people in the UK. However, older people may be more likely to be 'punished' for their deviant lifestyles than younger people. For example, Simmons & O'Brien (2000, p34) comment (without irony) that,

> 'The very fact that they have lived independently and fared reasonably well for many years inclines some older persons to think that they can continue to do so without paternalistic care or medical interventions'

Having a 'lack of shame' was one of the diagnostic criteria for Diogenes Syndrome (Clarke, 1975), and Clarke went on to describe the older people in his study as 'showing aggressive rudeness' (p801). Although these words would probably not be used today, Gawande (2017) discusses how coded language is used to describe negative behaviours in older people. For example, Gawande argued that the word 'feisty', rarely applied to younger people, is used to mean difficult or stubborn when applied to older people. He notes how staff 'like those 'who are 'fighters' and show 'dignity and self-esteem' – until these traits interfere with the staff's priorities for them. Then they are 'feisty'' (p76).

2.4.3 Gender and self-neglect

There are particular considerations around gender and self-neglect, though as Weeks et al (2018) note, gender-based analysis is often neglected by those working with or writing about older adults and abuse. Macmillan & Shaw (1966), writing about ‘senile breakdown’ stated that, ‘The usual picture is that of an old woman living alone’ and this became the received wisdom over the subsequent decades. However, when they wrote in 1966, women over the age of 80 outnumbered men by approximately two to one (Population Pyramid, 2018). Not only do women statistically outlive men, but in 1966 a person of 80, would have been 28 at the outbreak of World War One. Many men of this generation died, so the figures by 1966 were highly skewed[2]. Arguably, because there were many more women than men, it was more likely that self-neglect would be seen in older women than in older men – because the men were dead. It is not more likely, *ceteris paribus*, that women will self-neglect. However, writing in 2000, Simmons & O’Brien (p43), in a similar vein, argue that ‘when it comes to those over 80 years of age, women are two to three times more likely to be self-neglected’. This implies that there is something about the nature of women that makes them more likely to neglect themselves than men, rather than acknowledging the reality which is that more older women than older men are likely to come to the attention of services because women live longer than men.

However, Simmons & O’Brien (2000) do make an important point when they write that ‘Women are victimised by self-neglect more than males’ (p43). In general, as Löfgren, (2017,) notes, in relation to domestic order, it is women who are blamed for homes (or a person) that are not up to standard. Therefore, there will be more cultural opprobrium attached to a self-neglecting woman, than a man. That is compounded by the persistent stereotype of older women as ‘mystics and witches’, (Hughes & Mtezuka, 1992, p223).

The issue of poverty is seldom discussed in relation to self-neglect, though Clarke (1975), notes that some participants in his study ‘hoarded secret wealth and posed as paupers’ (p801). This

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[2] Current UK estimates for female life expectancy at birth are 82.8 years and 79.1 years for men (Age UK, 2018, p6)

view itself arguably contributes to the ‘urban legends’ (Best, 2013) surrounding self-neglect. Although we cannot know how many people who self-neglect or hoard are living in poverty, which may contribute to self-neglect and neglect of the environment, we do know that older women are more likely to be living in poverty than older men. In 2015 the average weekly amount of State Pension received by women was 79% that of the average for men (Thurley et al, 2015). Of the 2 million people over 75 in the UK who live alone, 1.5 million are women (Age UK, 2018, p3). Housing tenure is also important. A recent report from the charity Independent Age (2018) showed how, for the half a million older people living in privately rented accommodation, their situation was often precarious and uncertain, they were more likely to have problems with the suitability of their housing, and more likely to be living in poverty than homeowners.

2.5 The voices of those who self-neglect

Studies carried out with self-neglecters generally aim to understand *why* people should behave in this way. Reasons identified include pride in self-sufficiency, a sense of connectedness to place and possessions, and behaviour that attempts to preserve the continuity of identity and control (Bozinovski 2000; Lauder et al, 2009; Braye et al, 2011b; Orr et al, 2017). Lauder et al (2005b, p193) observe that ‘the overwhelming theme in discussions of people who self-neglect is their extreme reluctance to accept professional help’ (p193). Braye et al (2014a) identify a fear of being found out, that is, coming to the attention of the authorities, and this is echoed in online forums of hoarders. Few studies have considered the role of neighbours and communities, though a notable exception to this is May-Chahal & Antrobus’ 2012 study, which stressed the importance of early intervention, and considered the resources available in people’s own communities.

Lauder et al (2009) note that an omission from the literature is the perspective of self-neglecters themselves, and attributes this to the difficulties of recruiting this client group. Access to such individuals generally has to be negotiated via professional agencies (Social services, Health, etc.). Lauder et al (2005b) noted that ‘a great deal of very intensive work was required in order to secure a relatively small number of interviews’ (p3) and again in the 2009 study, that a great deal of effort was invested in working with government agencies which proved ‘expensive and time consuming’ (p449), and that in putting forward cases, agencies appeared ‘very anxious to recruit ‘success stories’’ (p451).

There are few studies which consider *how* service users would like professionals to work with them. This may be because the ‘extreme reluctance’ to accept professional help or intervention identified by Lauder et al (2005c, p193) may also extend to participating in the intervention of a research study. This reluctance may be compounded by the characteristics of many people who are seriously self-neglecting in respect of capacity, cognitive impairments, mental health conditions and so forth. Many people who are living in squalor and seriously self-neglecting (the focus of this study), will neither leave their homes nor allow others access to them (Snowdon & Halliday, 2012). It may not be appropriate or even possible for a researcher to gain access to these people, and it is likely that capacity to consent to participate would be questionable (Mental Capacity Act 2005). Lauder et al (2005b) found that the most successful approach to service users was via introduction by a professional where the service user had a good relationship with the professional involved in their care.

Braye et al (2014a) interviewed 29 people who used services, who spoke about the interventions they had experienced and the different approaches that practitioners used. The involvement of these service users was mediated by practitioners being interviewed for the overall study, who either knew and worked with them directly, or indirectly through support groups and so forth. This means the participants were arguably also biased towards being ‘success stories’, and also more open to intervention from services, because they were identified by those already intervening, as Braye et al (2014a) concede. They were also required to have capacity to give informed consent, which would exclude cases where assessment of capacity was problematic, though this is precisely the group of service users that practitioners struggle with. Because capacity is issue specific, it might be the case that a person could be deemed to have the capacity to decide to live in squalor (the 'lifestyle choice' argument), but not have the capacity to consent to take part in an interview, which means their voices would be lost anyhow. Some of those defined by professionals as self-neglecters did not identify themselves as self-neglecters and declined to participate. Like Lauder's 2009 study, a significant proportion of self-neglecters interviewed were homeless, which gave no insight into the circumstances of those living in severe squalor in their own homes.

2.6 Conclusion

In this chapter I have set the scene and provide a rationale for why I have chosen to focus on self-neglect as the complex issue at the heart of my research. My research aims to focus on how professionals respond to those who self-neglect, and how they work together to do that. This chapter has identified why self-neglect is a difficult area for practitioners to work in, not only because of the personal feelings that it may provoke, but also because it is so poorly defined and understood. The chapter has outlined important developments in the discourse of self-neglect, and how this impacts upon people working with those who self-neglect. In addition it demonstrates the need to dig below the surface to understand why self-neglect has increasingly come under the spotlight. There remain many unanswered questions about self-neglect, but one thing is, I hope, clear, which is that, 'Individuals who neglect themselves and their environment have only this in common; they are no more likely to be similar in other respects than are any two individuals selected at random' (Muir-Gray, 1988, p210).

In the next chapter I will explore the literature on multi-agency working, in relation to barriers and facilitators which may exist, and examine the particular issues surrounding multi-agency working in adult safeguarding and working with people who self-neglect.

Chapter 3 - Literature review – Multi-agency working

3.1 Introduction

In this literature review, I will critically analyse the literature on multi-agency working with adults who have care and support needs, looking at different facets of multi-agency working, the issues it presents and the resolutions that are suggested in the literature. Although central to contemporary health and social care policy in recent years (Morris, 2008), collaborative working, of which multi-agency working may be seen as a type (Whittington et al, 2009), is considered by some to be under theorised (Trivedi et al, 2013; Reeves & Hean, 2013; Auschra, 2018) and poorly evidenced (Redding, 2013; Dickinson, 2014; South et al, 2014; Kaba et al, 2016; Kaehne, 2017; Reeves et al, 2017). Auschra (2018) calls for more attention to be paid to the barriers to the integration of care across organisations, and notes that, 'there is a significant gap between what "could" be possible in collaborative practice and what actually is achieved within most inter-organisational relationships' (p2).

Such is the territory that this literature review will explore. I have taken a narrative approach to the review (Gordon, 2017) given the wide area being covered, an approach which can be useful to 'identify connections and synergies' (p1335) within a varied literature. Herr & Anderson (2015), in their guide to writing an AR dissertation, describe how, as the researcher gains a deeper understanding of the area of study, the pool of literature that is drawn on will develop likewise.

That closely describes my position, and because of this, the review is presented in two parts. The first part reviews the literature that I examined prior to beginning my fieldwork, where the emphasis was on multi-agency working in relation to the care of vulnerable adults, safeguarding and specifically self-neglect. During my fieldwork, as my awareness of the 'gap' (Auschra, 2018) between the possible and the actual grew, my literature review shifted emphasis to consider the actual barriers that I was hearing described by participants, and this is covered in the second part of the review.

3.2 Literature search strategy

The iterative process of writing this review is reflected in my literature search strategy, summarised in Table 2.

Table 2: Literature search strategy and sources searched

Type of literature	Search strategy	Source	
Academic literature	Online databases	ASSIA Cinahl Psychinfo Social care online SSCI	AgeInfo Medline Scopus Discover Cochrane Library
Academic Literature	Hand searches of journal databases	Journals	
Academic Literature	Hand searches of library catalogues	Books	
Grey literature	Google OpenGrey	Relevant PhD theses (held on ETHOS) Government reports Reports from charities (e.g. Action on Elder Abuse) Think Tanks (e.g. Institute of Public Policy Research) National Institute for Clinical Excellence Social Care Institute for Excellence Conference abstracts and presentations Private sector research British & Irish Legal Information Institute (BAILII)	
Trade 'e' journals & websites	Google	Community Care CC Inform Mental Health Law Essex Street Chambers Research in Practice for Adults Newspapers	
'Virtual literature'	Google	Blogs and Twitter feeds Webinars Local Authority websites 'You Tube' presentations	

Initially I conducted a database search, using both keywords and synonyms. I searched ‘multi-agency’, multi-agency working’, ‘joint working’, ‘collaborative working’, ‘multi-agency/adults’ and ‘multi -agency/self-neglect’. Although this study focusses on the situation in England, literature from the UK, America and Australia are included in the literature review, where relevant, for context and richness of reporting.

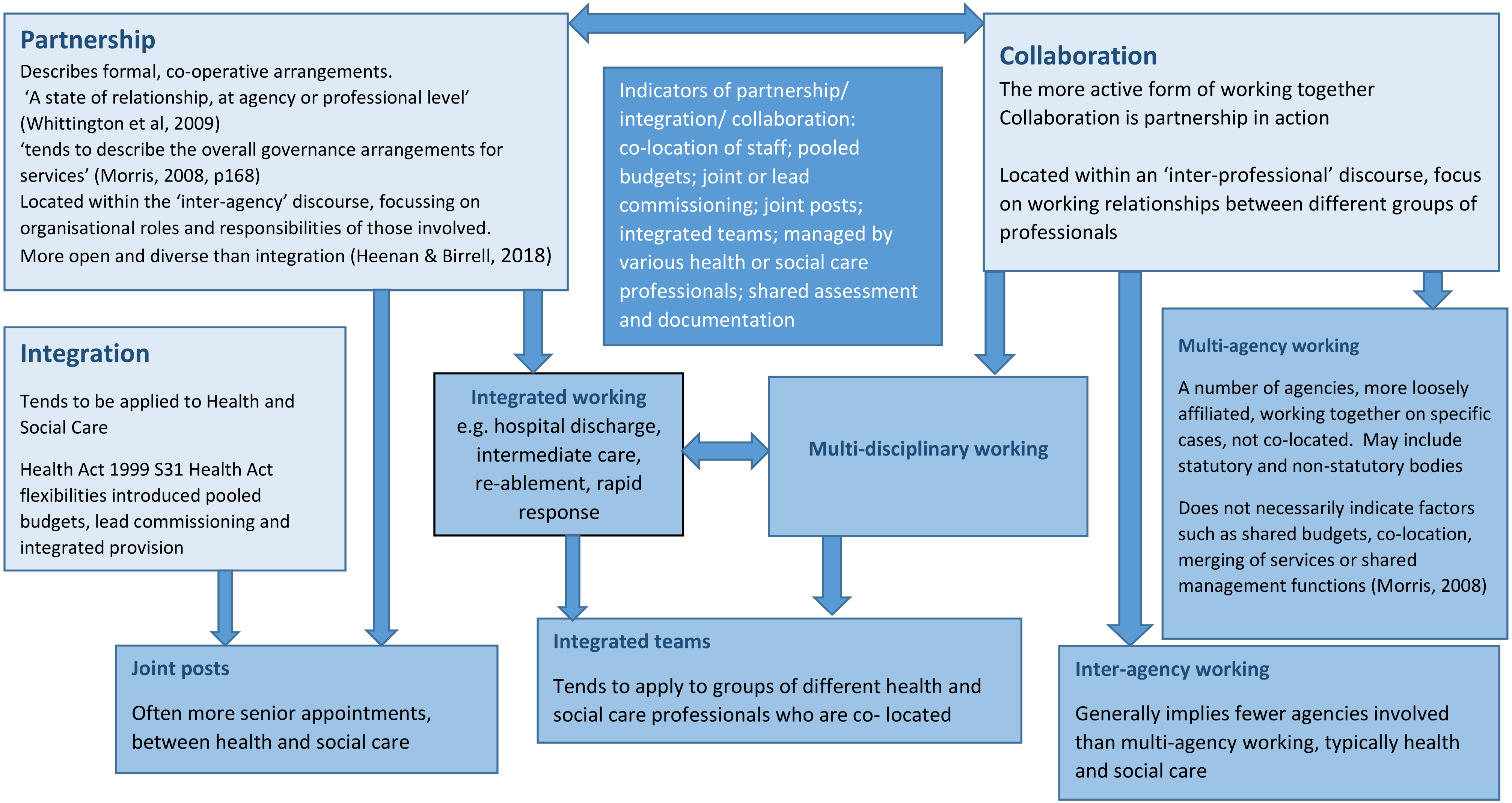
I found that a computer search of relevant databases using keywords and synonyms was insufficient owing to the terminological variation found in the literature around multi-agency working (Xyrichis & Lowton, 2008), and because many keywords that featured in my searches did not appear in the titles of articles that were relevant. For example, a search of Social Sciences Citation Index with key words ‘multi-agency’ and ‘self-neglect’ produced one (irrelevant) result. I realised that I would have to go beyond databases (Conn et al, 2003) to find the relevant literature. As this thesis was set in a context of a developing legislative and policy field, it was clear that important sources might sometimes be located in the grey literature, rather than the conventional academic literature, and so this proved (see Table 2 above).

As the literature review progressed, I began to make extensive use of hand searching of key journals, scanning tables of contents and the annual index (Schlosser et al, 2006). I set up journal alerts to a number of journals, which have increased as the research has progressed, and examined abstracts. As I began to be able to identify important authors and key articles in the field, I employed the technique of ‘ancestry searching’ (Conn, 2003), searching through the references of relevant articles, chapters and books for relevant citations. I also carried out ‘forward citation searching’ using Google Scholar, whereby one takes an identified citation or reference and tracks its after-life to identify subsequently published sources that have cited this reference (White, 1994). I found that using these techniques overcame the problem of keyword/synonym searching not identifying relevant articles. However, it also widened the potential keywords, which ultimately meant I incorporated other search terms, namely ‘partnership’; ‘integration’ and ‘inter-professional’. In this, I was following Cameron et al, who searched similarly broadly in their 2003 and 2014a literature reviews of joint working. As Figure 1 (below) shows, some of these search terms are associated more with the formal integration agenda, though as Heenan & Birral (2018) note, there is no broadly accepted definition of integration in the literature. This range of terminology is reflected in the literature review, where I have tried to be reasonably consistent in terminology, but also to reflect the terminology used by the authors I am referencing.

It is also important to note that there is a common split in the literature between the organisation of services for adults and for children. The day-to-day operation of services for children and adults in the UK is distinctive in each case, being governed by completely separate legislation and policy (Flynn, 2008). However, whilst I have largely focused on literature in relation to adult services, following Sloper (2004), I have on occasion referred to the literature from children’s services where I felt important points were being made that applied equally to adults.

Reflective stop off
One of the advantages of studying a developing area like self-neglect and multi-agency working is that many of the key authors are actively promoting their work, via conferences and publications for example. Once I had identified key authors, in two cases I emailed them to ask for further information about their research as McNiff, (2017) suggests. In one case this was forthcoming, in another not, which in itself was an interesting outcome. I was also able to do this in two cases at conferences following a presentation, and at another conference I was co-presenting alongside one of my identified experts, so was able to hear them discuss their research and speak with them afterwards.

Figure 1: Joint working terminology map



Partnership

Describes formal, co-operative arrangements.
'A state of relationship, at agency or professional level' (Whittington et al, 2009)
'tends to describe the overall governance arrangements for services' (Morris, 2008, p168)
Located within the 'inter-agency' discourse, focussing on organisational roles and responsibilities of those involved.
More open and diverse than integration (Heenan & Birrell, 2018)

Indicators of partnership/ integration/ collaboration: co-location of staff; pooled budgets; joint or lead commissioning; joint posts; integrated teams; managed by various health or social care professionals; shared assessment and documentation

Collaboration

The more active form of working together
Collaboration is partnership in action

Located within an 'inter-professional' discourse, focus on working relationships between different groups of professionals

Integration

Tends to be applied to Health and Social Care

Health Act 1999 S31 Health Act flexibilities introduced pooled budgets, lead commissioning and integrated provision

Integrated working
e.g. hospital discharge, intermediate care, re-ablement, rapid response

Multi-disciplinary working

Multi-agency working

A number of agencies, more loosely affiliated, working together on specific cases, not co-located. May include statutory and non-statutory bodies

Does not necessarily indicate factors such as shared budgets, co-location, merging of services or shared management functions (Morris, 2008)

Joint posts

Often more senior appointments, between health and social care

Integrated teams

Tends to apply to groups of different health and social care professionals who are co- located

Inter-agency working

Generally implies fewer agencies involved than multi-agency working, typically health and social care

To evaluate the usefulness and relevance of empirical studies that I had identified, I used the SPIDER framework (Cooke et al, 2012, p1348). The acronym stands for:

- Sample (tends to be smaller groups, so sample rather than population)
- Phenomenon of interest (the how and why)
- Design
- Evaluation (may be attitudes, views etc.)
- Research type (quantitative, qualitative, mixed)

Following Cameron et al (2014a) I also considered whether there was a clear rationale for the study, a clear explanation of the methods and a clear articulation of the outcome measures.

3.3 Terminological complexity

Various terms are used in the literature to denote the organisation of professional practice (see Figure 1 above), which are often used interchangeably and loosely (Pinkney et al, 2008; Dickinson & Glasby, 2010; Beaulieu et al, 2017). For example, the term ‘partnership working’ can encompass a spectrum of meaning, from,

> ‘as little as meeting together with others to share information and intelligence, to more grandly, developing integrated services and approaches that mean that people no longer have to concern themselves with who is the provider’ (Thomas, 2015, p197).

This study focuses on multi-agency working in relation to self-neglect. Atkinson et al (2007) note that ‘Multi-agency activity takes many forms and the terminology used to describe it varies, making classification and comparison between different types difficult.’(p2). Dickinson (2014) echoes this in stating that reviews of literature on factors influencing multi-agency working are often ‘ill-defined or so broad that they might refer to a range of different phenomena’ (p191). Morris (2008) defines multi-agency working as, ‘the arrangements and processes for a number of single agencies to come together to plan and deliver services that have shared aims and outcomes’(p167), which implies a level of collaboration that may not in reality be present. Horwath & Morrison (2007), themselves drawing on the literature, give five levels of collaboration,

1. Communication: individuals from different disciplines talking together.
2. Co-operation: low-key joint working on a case-by-case basis.
3. Co-ordination: more formalised joint working, but no sanctions for non-compliance.
4. Coalition: joint structures sacrificing some autonomy.
5. Integration: organisations merge to create new joint identity. (ibid, p56)

The kind of multi-agency working that I am considering perhaps falls best into the area of 'co-operation'. Multi-agency working in self-neglect (and safeguarding) is distinguished by being ad hoc and fluid, established on a case-by-case basis according to the exigencies of that case. The guidance to the Care Act 2014, refers to this as 'targeted co-operation' (DoH, 2016, para 15.27). Such working may have elements of co-ordination and coalition, but this will only be likely between some agencies within the overall picture. It does not tend to have the characteristics of integrated working described by Kodner & Spreeuwenberg (2002) as,

> a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors (p3).

In a recent systematic review of the effects of integrated care, Baxter et al (2018) identify 25 elements of models of integrated care, including several which would also characterise multi-agency working, such as joint assessment, or multi-disciplinary meetings. Furthermore, in the context in which this research is set, some agencies within the co-operative group, notably health and social services, are currently working towards greater integration, which brings added complexity to the multi-agency working situation. Similarly, the term 'inter-professional working' is used frequently in the literature. Trivedi et al (2013) define this as being distinguished by shared care plans and shared protocols, and face-to-face team meetings, some of which may also be present in multi-agency working, or between some of the agencies in the wider multi-agency picture.

Shared aims and outcomes are by no means a given, depending on the legal remit of the individual agencies, the aims of their service, and the degree of integration between those services (Horwath & Morrison, 2007). Probably the most frequently involved organisation in a self-neglect case will be local authority social services (LASS) (Morris, 2008), because of their safeguarding responsibilities under the Care Act, but this will not always be so, and there will be self-neglect cases where LASS are not involved. The professionals working on a self-neglect case at a 'co-operative' (Horwath & Morrison, 2007) level will not generally be co-located, though *some* of those involved may be. The most likely to be co-located are social services and some health staff (though not all), and potentially the police, as in the case of 'Multi-Agency Safeguarding Hub (MASH) teams (Home Office, 2014). In such 'low level collaboration' (Horwath & Morrison, 2007), agencies are likely to retain control of their own resources and funding, remain autonomous, work towards different targets, and be focussed on individual cases (p57). For the professionals involved this is likely to mean they retain affiliation to their own agency, to which they are accountable, and within which they are managed (ibid).

3.4 Part 1: Issues in the literature on multi-agency working in adult care

3.4.1 Multi-agency working in adult care

Existing studies of multi-agency working in the wider adult care arena consistently highlight areas of difficulty. A recent example is the study of practitioners in the UK within multi-agency teams in an integrated Trust providing health and social care services, carried out by Phillipowsky (2018). The study found participants reported conceptual confusion, cultural biases and culture clashes, a lack of mutual knowledge, a lack of strategic vision, and problems caused by the impact of financial cuts. Although this study looks at a multi-agency team, rather than the looser multi-agency working conceptualisation which characterises self-neglect work, this is an interesting study as it is the only one to consider the impact of austerity on collaborative working. However, the majority of respondents were social workers, who were being asked about their perceptions of their own role, though the same survey was used to ask other professionals about their perceptions of the role of social workers, i.e. the participants were being asked their perception of different things. There is also the possibility of bias, as Philipowsky appears to have been employed by the Trust in which he carried out the research, although this is not directly stated. Abendstern et al's (2010) study of integrated assessment within older people's services suggested that whilst there was commitment to integrated working, disjointed information hampered sharing initiatives and caused lack of involvement from some groups. They found that training on using new processes had focused on developing skills rather than 'on issues that aimed to develop trust and understanding between different professionals' (p15). However, a limitation of this study is that it utilised survey data which had been gathered for a national survey five years before the publication of the 2010 paper. Abley et al's (2011) study of the inter-professional understanding of vulnerability for older people highlights the difference between *emic* vulnerability (the individual's personal interpretation of their situation) and *etic* vulnerability (externally evaluated risk), a highly relevant concept for self-neglect work, and calls for increased inter-professional training, joint goals and trust between team members.

3.4.2 Multi-agency working in safeguarding adults

Studies looking at joint working practices employed by agencies that support vulnerable people through the safeguarding process are uncommon (Joseph et al, 2019). For the purpose of this review, it is useful to consider what can be extrapolated from studies of multi-agency working in safeguarding adults prior to the implementation of the Care Act 2014, as both safeguarding and multi-agency working were previously established concepts, though they did not include self-neglect. Brown & Stein (1998) published one of the earliest studies in this area. Though this study is described as being within an action research paradigm, it centres on counts of referral numbers, types of abuse and so forth, very much a prototype of the safeguarding statistics that are collected today. Frustratingly, it gives no detail of the extent and type of involvement of participants, though practitioners here were reported as wanting more information about the legal framework and (predating the MCA by eight years) capacity to consent.

In 2000 the first formal policy on safeguarding adults, *No Secrets* (DoH, 2000), was introduced by the then Labour government. An excellent study in 2008 by McCreadie et al, in eight local authority areas, interviewed NHS staff, police, provider agency staff, housing and social services staff, who were responsible for developing multi-agency safeguarding procedures. They found confusion due to differing interpretations of what constituted both a 'vulnerable' adult and abuse. It was also of concern to the participants that some agencies had either been excluded from, or abdicated, their responsibilities in relation to developing the procedures. In terms of individual practice, they found that respondents misunderstood each other's roles and were 'unfamiliar with, mystified by, or even opposed to' (p254) other agencies' roles in the procedures. However, they identified a great advantage for agencies working together, that of being able to shield individual agencies from liability when things went wrong (ibid). Anetzberger et al (2004) frame this in a more optimistic way in suggesting that multi-disciplinary teams working in elder abuse can bring a more holistic perspective, can share the responsibility for difficult cases and can promote a more joined-up approach.

Johnson (2012) employed a case study approach in her research, looking at inter-agency safeguarding practice. A weakness of her approach was that the cases used were very general and appeared to have few parameters. She found that practitioners operated 'implicit practice rules' which differed from the 'explicit policy criteria' that they were supposed to follow (p203), and this had implications for different groups of service users, where an issue that might be taken seriously and cause policy and procedures to be followed for one person would not be treated in the same way for another. This may be particularly relevant for those working in areas of high professional uncertainty, such as self-neglect. Braye et al's (2014a) study touches on where self-neglect ‘sits’ in relation to safeguarding, and one respondent notes that, where an issue is treated as safeguarding, capacity and risk assessment are ignored in the ‘rush to raise a safeguarding referral’ (p26).

Fyson & Kitson (2012), using a novel approach of asking local authority staff to complete a short form about the five most recent cases they had managed, analysed outcomes following safeguarding referrals. This study included a relatively small sample in one local authority, and had considerable confidentiality implications. Nonetheless, the authors found that one of the important variables in cases reaching a conclusive outcome was inter-agency co-operation, and, in particular, multi-agency meetings. Graham et al’s (2014) review of literature also notes considerable consensus on the benefits of inter-agency working. However, Steven’s (2013) literature review notes continuing professional confusion over roles, responsibilities and thresholds.

A recent study by Joseph et al (2019) reports on Phase 1 of a study, funded by the Scottish Institute for Policing Research (SIPR), and intended to review the ‘state of play’ (p50) in inter-agency collaboration in safeguarding adults between the police and health and social care professionals. No explanation is given for why these particular groups were chosen. The paper reports on focus groups held with police, social care staff and ‘Health’ (sic), albeit the numbers of police staff in the study far outweigh the number of social care and health staff. Although this is described as ‘representative numbers’ (p53), the assessment of what is ‘representative’ is not made clear, in terms of statistics. As the study is funded by the SIPR, this raises concerns about bias. In addition, although the study included social workers and ‘other professionals working in social care’ (ibid), it is unclear who these might have been. No attempt is made to describe who the ‘Health’ staff were. It is therefore not possible to tell if these are staff with particular responsibility for adult safeguarding. Focus groups were uni-professional, but no rationale is given for this. The study adopts what it describes as a 'modified realistic evaluation approach' and uses 'context-mechanism-outcome' analysis (ibid, p60), both of which appear to over-complicate the findings. However, recommendations from the study included the improvement of information sharing and joint education and training, which supports findings from other studies already discussed here.

3.4.3 The construction of multi-agency working and safeguarding

It can be argued that the concept of multi-agency working, and associated concepts such as integration, are in themselves social constructs, as originally described by Symonds & Kelly (1998) in relation to the development of community care in the 1990s. For example, Hopson (2013, np) argues that integration is 'the latest mantra for improving care', whilst Clements (2014, p2) discusses the 'degree of 'integration frenzy' in political policies.   Haynes (2001, p263) argues that the construction of the concept of multi-agency working is a result of moral panics over specific social issues, such as youth crime or substance misuse.   Ash (2014) posits that multi-agency working in safeguarding adults has been developing since the 1990s, as 'the coalescence of policy and professional concerns in the UK developed into the social policy 'naming' of elder abuse as a social problem' (p25), and Johnson (2012) can be said to support this with her argument that safeguarding adults policies are themselves a construction, 'in the sense that they interpret certain kinds of events or circumstances to represent certain types of problems' (p204).

In a reflective piece on a case review of a female adult, Scourfield (2010) raises the question of whether serious self-neglect cases *should* be regarded as safeguarding issues, and what the implications of constructing them in this way are. He speculates that the emergence of safeguarding as a key issue in the last two decades has led to such situations being viewed through the safeguarding lens, and questions what the impact of this might be on service users in particular.

The 'claims making' (Spector & Kitsuse, 2006) around multi-agency working as the most desirable, if not the essential way of working in the area of safeguarding adults is now formalised in the legislation which compels agencies to work together. This is the result of decades of policy development and a good example of constitutive juridification, the process by which new norms are established to eventually become law (Blichner & Molander, 2008).

3.4.4 Multi-Agency working, Safeguarding Adults Boards, and the duty to co-operate

The Care Act 2014 makes it mandatory for all local authorities in England to set up a Safeguarding Adults Board (SAB), ideally involving all of the partners with whom local authorities might work, ‘to help and protect adults in its area in [safeguarding] cases’ (Care Act, s43.2), and these are crucial in providing ‘top down’ (Matland, 1995) direction for multi-agency working in adult safeguarding. In reality, many authorities had done this prior to the Care Act, and a study by Braye et al (2012) found that setting up a SAB could in itself be problematic, with the number of SAB members in the study sample ranging from 10 to 47. Manthorpe et al (2015) analysed the content of 19 SAB annual reports, and highlighted complete lack of standardisation between the documents. This is a good example of Matland’s (1995) concept of high policy ambiguity, because there is no prescribed ‘way’ of doing the business of a SAB, in relation to which agencies attend and how their work is reported and disseminated.

Braye et al (2012) summarise findings from other studies, about factors which can disrupt the good intentions of boards, including lack of knowledge of the law, clashes of organisational cultures, attitudes, priorities and thresholds, and limited knowledge of collaborative working. Penhale et al (2007) found that the inclusion of groups such as voluntary and private providers on to SAB’s was not routine. Thomas (2015) in a reflective paper, explores some of the cultural barriers to participation for third sector providers. Although this is a highly personal and subjective paper (the author is manager of a housing association), it nonetheless makes some important points, such as people from the third sector not being seen as full 'colleagues' by local authorities and others, because they work for private agencies rather than state-funded organisations.

The Care Act also introduced a duty for local authorities and their partner agencies to 'co-operate generally' (S6) and to 'co-operate in specific cases' (S7). In addition, 'A rather wide and somewhat ill-defined power has been created to demand information from anyone… that the SAB considers is likely to have information relevant to a function of the SAB' (Carr & Goosey, 2017, p139). The significance of these legal requirements for this study is that multi-agency working is no longer a matter of informal co-operation, but is legally mandated.

3.4.5 Multi-agency working and Safeguarding Adults Reviews

The Care Act 2014 established a duty on SAB's to carry out a Safeguarding Adult Review (SAR) whenever an adult dies or suffers serious abuse or neglect, and there is 'reasonable cause for concern about how the SAB, members of it or other persons with relevant functions worked together to safeguard the adult' (Care Act, 2014, S44(1)). The predecessors of these SAR's were Serious Case Reviews (SCR's) which many local authorities were carrying out prior to the Care Act, but which were not a legally imposed duty. Braye et al (2015a), report on the analysis of 32 SCR's in relation to self-neglect, and note,

> Professionals were confused about where responsibility lay between or even within agencies, and struggled to coordinate who would do what and when. The more agencies that became involved, the more marked was the failure to join up their efforts. (p82)

It is not stated how many of the SCR's studies came to these conclusions, however, Preston-Shoot (2018), also an author on the paper above, identifies disproportionately high numbers of SAR's relating to self-neglect since the introduction of the Care Act 2014. Preston-Shoot (2016; 2017; 2018) has extensively studied SAR's and SCR's in relation to self-neglect cases, and in his most recent study (Preston-Shoot, 2018) he considers common criticisms from reviews of what he terms the ‘professional team around the adult’ (p9) – the multi-agency group of practitioners working on a particular case. He notes that ‘familiar criticisms continue of silo working, rigid eligibility thresholds and inflexible agency responses’ (ibid). In addition, he draws out issues such as lack of awareness of what other agencies are offering, failure to clarify roles and responsibilities, lack of shared perspectives, lack of multi-agency meetings, and absence of escalation policies.

Although the reports produced by LSABs present a useful snapshot of multi-agency working on self-neglect cases, they may have limited general applicability. Flynn & Brown (2017) believe the reports act as a form of qualitative research in uncovering the ways in which safeguarding policies operate. However, they must be treated with caution, for as with SAB annual reports mentioned above, Aylett (2016) argues that there is little consistency between them. There is no centrally prescribed format for SAR’s, no national repository of reports, and no requirement that Boards publish their SAR’s, though many do. It is possible therefore that the SAR’s that are published represent less damning findings for example, than those which remain unpublished and out of the public eye.

Additionally, Aylett (2016) makes the point that SAR’s ‘tend to represent an organisation response which gives the appearance of creating stability for future responses by creating rules to follow’ (ibid, p35). This could be seen as an example of Dickinson’s (2014) point made earlier about Integration as a ‘science’ which, in the case of SAR’s, aims to isolate specific factors that can stop things going wrong, in order that these can become ‘the rules’ or the science of prevention. Flynn & Brown (2017) question how much systematic learning takes place from such reviews.

3.4.6 Multi-agency working in self-neglect

There are a limited number of studies of multi-agency working with people who self-neglect. What is striking about this literature, both from the UK and elsewhere, is that the recommendations made are often borne out of studies involving only one or two professional groups, although usually recommending good multi-agency working as a potential solution (see for example Pinkney et al, 2008). A study of hoarders in the US (Frost et al, 2000) found that in most of the cases they looked at, multiple agencies were involved, so the dearth of true multi-agency studies since then is perhaps surprising. Braye et al (2013) noted that referrals for self-neglect could come from a wide range of sources and that there were a wide range of professional groups involved in self-neglect, 'including practitioners at very different levels of qualification and experience' (p41). The studies that there are, discussed below, are usually based on small sample sizes, and explore perceptions of participants. Therefore any conclusions that are drawn may be unreliable.

The majority of studies in this area focus on social workers. The Social Care Institute for Excellence (Braye et al, 2014a) published a comprehensive report on self-neglect and social work which includes a national survey on the volume, challenges, practice and outcomes of self-neglect cases from local authorities across England (albeit with a low response rate of just 35% of authorities), but this only includes social work staff. Braye et al's 2013 workforce development study for the organisation Skills for Care also predominantly features social work staff. Some of the dilemmas for practitioners working with self-neglect are explored by Day *et al* (2012) in an exploratory Irish study of social worker views which, despite a very small sample size (seven people), does clearly define its rationale and aims. 'A multi-disciplinary approach' (p739) is identified as an important intervention strategy in working with people who self-neglect, but the authors do not offer any suggestions as to what this might look like. Brown and Pain (2014) in a highly descriptive study highlighting the work of one London authority in relation to hoarding, note that there ‘is little precedent of how any agency or local authority should respond, let alone social workers’ (p213). This seems to imply that social workers should have a different response to others, but it is not expanded upon in the article.

McDermott (2008) conducted a study of how adult protective services workers in Australia understood self-neglect. She utilised both observation and interviews, but with a small, though professionally heterogeneous, sample. She found that participants reported difficulties in defining self-neglect, hoarding and squalor, and that this led to subsequent blurring of organisational responsibilities, with frustrations ensuing between agencies seen as neglecting their responsibilities.

Some studies have included more than one professional group. Lauder et al (2005b; 2005c), looking at issues around self-neglect and housing, carried out individual interviews with 13 social workers, 3 environmental health officers, 12 housing workers and 3 healthcare workers, although participants did not meet. It is difficult to assess the impact of this disparity of numbers. Although it may be minimal in terms of the resultant analysis, it is hard to see how the views of the better represented groups could fail to predominate. They found different approaches to, and different definitions of self-neglect amongst the various staff, and overall a feeling of being ‘confounded by the range and complexity of cases’ (ibid, p322). Importantly, they suggested that if multi-agency interventions were better coordinated, it could help to conserve resources. This was the only study to suggest this cost saving issue. A significant recommendation of this study was that agencies needed to be better informed about each others’ potential remits in relation to self-neglect, and that initiatives such as joint training were important to increase the effectiveness of multi-agency working.

However, it would appear that joint training has been slow to establish. Ten years later a study by Day & McCarthy (2015) examined levels of knowledge of self-neglect held by social workers and nurses, concluded that there was a need for interdisciplinary training. Chapin et al (2010), in a mixed methods study using case file analysis and interviews, looked at referrals to multi-agency hoarding teams in the USA. They identified barriers to multi-agency working as including lack of an evidence base for successful intervention and lack of shared assessment tools. They found that referral to another agency was the action used most often and argued that repeated cycles of referrals to agencies makes it crucial to co-ordinate intervention, rather than just referring the problem on to others.

Koenig et al (2013) in another American study looked at multidisciplinary team perspectives on hoarding and mental illness in older adults. Although this was a small, qualitative study it included a range of different professionals. They identified successful collaborative working in this area as being dependent on, amongst other things, how well the professionals involved worked together to address multiple issues such as role conflict. The study showed that agency policies, and the ability to arrive at a shared understanding of the issue, could affect team success in working together.

Braye et al (2013) in a scoping study of workforce development for the organisation Skills for Care, aimed to enquire into 'the range of social care workforce groups involved with self-neglect' (p5) and the 'perceived workforce development needs in different agency contexts' (ibid). However, the study draws heavily on Braye et al's (2011) report for the Social Care Institute of Excellence (Braye et a, 2011b), and it is clear that their focus remains on social care staff, as evidenced by the composition of the focus groups used in the 2013 study. Out of 48 participants, 4 are listed as coming from 'partner agencies', defined as 'services distinct from adult social care (e.g. police, health, housing and fire services)' (p10). Although 6 further supported housing staff are listed, there was therefore one representative each from the police, health and fire services, and it is not stated what their role was or how they were placed to report on ‘perceived workforce developments needs’ in their agency. Findings from the focus groups included that although many workforce groups could be involved in a case, no respondents reported a systematic way of allocating self-neglect cases to these different groups. Variations in thresholds for intervention between different agencies were also recognised, particularly that the emergency services may have lower thresholds for intervention than social care, which resulted in a pressure on social care to ‘do something’ (ibid, p43)

3.4.7 Studies of frontline staff

Studies of multi-agency working in self-neglect (and wider safeguarding) have a tendency to focus on the experiences of more senior practitioners, and to propose solutions related to inter-agency collaboration at a senior level. For example, Lauder et al’s ESRC study (2005b) used workshops for ‘experts’, while Manthorpe et al’s (2010) study of managing relations between different agencies in adult protection only interviewed managers. Braye et al’s (2011b) study involved 44 safeguarding leads from local authorities (reasonably senior positions involving little or no direct client contact), police and health services, though in what proportion is not stated, but only 7 practitioners. The very fact that they make this distinction indicates that the safeguarding leads were not engaged in front-line practice. Similarly, Noga et al’s (2016) study using action learning with the police and partner agencies looked at the implementation of new procedures. The study achieved good multi-agency representation, albeit at managerial level; although, as the authors note ‘some managers preferred to attend meetings accompanied by a frontline practitioner’ (p137). This may suggest that activity around integration is more evident at the level of management and strategy, rather than that of practice (Challis et al, 2006).

Braye *et al* (2014a, p42) identify six themes in relation to ensuring good multi-agency co-operation: ‘getting sign-up’, ‘locating self-neglect within overarching multi-agency structures’, ‘systems used to facilitate multi-agency working’, ‘different perspectives on ethical dilemmas’, ‘assigning lead responsibility’ and ‘how particular agencies are participating’, but many of these are outside the remit and influence of individual frontline practitioners. It is interesting therefore to note that many of the mechanisms explored to enhance multi-agency working in the study are themselves at senior or policy level (advisory panels, high-risk panels, Vulnerable Adult Risk Management Systems). No studies were identified which explored the experience of those staff providing day-to-day support to people who self-neglected, such as home care workers, support workers or nursing assistants, or which considered their role in the multi-agency picture.

3.4.8 Multi-agency working and professional judgement

There are unquestionably problems in how consistent professionals are in identifying vulnerability (Aylett, 2016), and existing studies of professional judgments and decision making in self-neglect reflect this. Byers & Zeller’s (1995) study of adult protective services workers’ judgments in the USA used vignettes to explore whether workers judged self-neglecters responsible for their own situations, and what victim and case characteristics they used to arrive at this judgment. They concluded that the substance of the law and the person’s disability were key factors in professional judgments. Conversely, Lauder et al’s (2001) survey of nurses’ judgements, again using vignettes, identified that the use of self-care behaviours was the most powerful influence on their self-neglect judgements.

McDermott’s (2010) Australian study uses critical theory as a framework for interpreting the findings. This was a study looking at professional judgements made by a variety of practitioners in relation to older people who self-neglected. Using a combination of observations and interviews with professionals, from both housing and health, she found that professional judgments of self-neglect focus on risk and capacity, and these perceptions can influence when and how interventions occur. She argues that the proliferation of biomedical explanations of self-neglect (as discussed in Chapter 2), which ignore its social and cultural context (Lauder 1999), may have obscured the important influence of professional judgments in shaping understandings of, and responses to, self-neglect. The study demonstrated that perceptions of risk were key in shaping professional judgements, and that professionals were strongly influenced by their own organisational context. Health professionals focused on risks to the person, whilst housing staff focused on environmental risks. Arguably, this is an obvious conclusion, but it does suggest why it might be difficult to reach multi-agency consensus in some cases. McKenzie et al (2001), in their study of duty of care, found that health care staff had a significantly broader understanding of the concept of duty of care and were significantly more likely to emphasise client safety implications than social care staff.

In a further study using the same data, McDermott (2011) also notes how the two groups of professionals interpreted autonomy in different ways. When decision-making capacity was demonstrated by self-neglecting people, health practitioners in the study took a stance of non-interference, with the intention of encouraging autonomy. Conversely, housing staff believed it was important to protect people from harm even if they had capacity. The latter stance reflects the ethical principal of beneficence, which McDermott discusses at the start of the paper, but does not develop. Unsurprisingly, these differences caused tensions between the two groups.

Killick & Taylor (2012) in their Irish study explored professional judgments in elder abuse referrals and found variations in the recognition and reporting of abuse. This echoed Preston-Shoot & Wigley (2002) in their finding that in complex situations practitioners may act more autonomously rather than follow procedural guidance. This has clear implications for multi-agency working in self-neglect. Lauder et al (2005a) believe that the challenge (to nurses in this case) is to examine what is taken for granted and to question, critically, the validity of the labels and motivations that are ascribed to those who self-neglect, and they note that professional judgments may vary within an interdisciplinary team. Dong & Gorbien (2005) note that when multi-disciplinary teams come together to help a client, they may not share the same ethical standards and must 'learn to work together with each other's respective ethics protocols … it is critical that each discipline educate each other' (p30). How they do that may not be quite so straightforward, and Braye et al (2014a) note that different perspectives on ethical dilemmas are a challenging issues for multi-agency working in self-neglect.

3.4.9 Multi-agency understanding of mental capacity, autonomy and vulnerability

Key to determining multi-agency understandings of and responses to, people who self-neglect in England and Wales is the Mental Capacity Act 2005 (MCA 2005). This Act introduced a framework for establishing decision-making capacity (Dong & Gorbien, 2005) in adults, to be adhered to by all professionals working in this area. Lauder et al (2005a) noted that recognising when people *can* make decisions for themselves, and when professionals are simply imposing their own beliefs about what is socially acceptable are at the heart of the balance between autonomy and control. They further noted that the lack of a test that could be applied to establish capacity was a hindrance. Such a test, contained in the MCA 2005, should now be familiar to all adult care practitioners, and have led to clearer multi-agency decision making, but seems, in practice, to have led to confusion about when to intervene (House of Lords Select Committee, 2014; Braye et al, 2014; Hinsliff-Smith et al, 2017; Shepherd et al, 2018). Reports from SAR's have consistently criticised capacity decisions and multi-agency working (Preston-Shoot, 2018). Providing staff with formal training on capacity appears to have a limited effect (Wilner et al, 2013),

A systematic review by Hinsliff-Smith et al (2017) of the application of the MCA 2005 in healthcare practice with frail and older people identified three themes in the literature, two of which are

relevant here. These were poor knowledge and understanding of the Act and tensions in applying the Act in everyday practice. However, the studies they identify tend to focus on one professional group or setting. A small study by Ratcliff & Chapman (2016) carried out interviews with 8 staff on a community learning disability team with different professional backgrounds. They identified a degree of professional role conflict as to who was best placed to complete the assessment.
A recent study by Shepherd et al (2018) examined health and social care professionals understanding of proxy decision-making as set out in the Act. Using vignettes in an online survey, the study found very high levels of discordance between participant responses and the actual legal framework. However, the study was specifically looking at the use of the MCA in research participation, so it is unclear whether the findings might be extrapolated to a wider context, and the authors rightly state that this area requires further research.

Participants in Braye et al's study (2013) discussed above, identified mental capacity as a complex but central factor in assessment and interventions with people who self-neglect. Dong & Gorbien (2005) suggest professionals should view decision-making capacity as a spectrum rather than a simple dichotomy. Unfortunately, not only may different professionals have different views about where a self-neglecter sits on any spectrum (Ruck Keene, 2017), the current legal framework does not support this more nuanced approach, as the MCA operates a binary concept of capacity, requiring a simple yes/no decision.

Emmett et al (2013) argue that the boundary between those who do and do not possess capacity does not deal adequately with those whose decisional capacity is marginal (such as people who self-neglect), and that a more comprehensive, contextual approach is needed. Mackenzie & Rogers (2013) suggest that welfare professionals must move beyond a primarily cognitive approach to capacity assessment to a range of more demanding autonomy conditions.

Where it has been demonstrated that a person has capacity to make a particular decision, the MCA 2005 states that they must be allowed to do so however unwise or eccentric that decision may seem. Ash (2014, p70) calls this 'the right to make bad choices'. Preston-Shoot & Wigley (2002), in a study which predated the MCA 2005 but which remains pertinent, used interviews, case analysis and a survey to explore the application of safeguarding procedures by professionals in a multi-agency context. They found many staff saw self-determination as more important than protection, and what was viewed as 'choice' being acceptable, even when this led to risk. Similarly, Koenig et al (2013) found that practitioners 'lean toward honouring self-determination, even when they see the dangers' (p73), and McDermott (2010; 2011) echoes this finding. This is crystallised by one of the participants in Braye et al's study (2014a), a concerned family member who cannot understand how,

> People [with a diagnosis of Diogenes Syndrome] don't have a choice, yet on the other hand, authorities and whoever were saying she does have a choice… I felt as though we were falling between two stools, like she's got a choice to live like that, but she has got a mental condition so she hasn't got the mental capacity (p111).

A paper by Mason et al (2018), though not an empirical study, brought together social workers and homelessness workers in 'community of practice' meetings. An issue raised in regard to self-neglect referrals to the SSD, was the concern by homelessness practitioners that social workers gave primacy to autonomy, 'without respectfully challenging why the person was refusing care and support' (ibid, p7). In a similar vein, McDermott (2011) notes that overemphasis on autonomy can provoke tension between service providers and can result in 'reverse ageism' (p67), where dignity and respect towards dependent older people are sacrificed in the name of autonomy (Moody, 1998).

However, there is a lack of unanimity over whether self-determination can or should be the guiding principle in self-neglect cases, because of the duty of care that all professionals assume, and conflicting concepts such as dignity (Preston-Shoot, 2001; Flynn et al, 2003; McDermott et al 2009; Scourfield, 2010). As Lauder et al (2005a) note, in their study of nurses,

> Even if nurses judge that this group of self-neglecting people are autonomous individuals who choose to live a squalid lifestyle this does not mean professionals should necessarily allow them to exercise this autonomy (p50).

Flynn et al (2003), in their study of health choices for people with learning disabilities, argue that 'People's 'choices' should not render them unprotected in services' (p33), and Gill & Qulsom (2013) argue that privileging choice for service users can leader to a derogation of the duty of care. Preston-Shoot (2001, p4) asks 'How might the balance between protection and self-determination, between individual freedom and professional intervention be calibrated?', and these are crucial questions for multi-agency working in self-neglect. The requirement of the Care Act duty to investigate self-neglect as part of safeguarding, whilst accepting that people who have capacity must be allowed to make unwise decisions, presents professionals involved with many such dilemmas. The House of Lords Select Committee (2014) report on the MCA was critical of health and social care practitioners for being risk averse and paternalistic and for over-emphasising protection, when the focus of the Act was to 'allow a protected person to make the same mistakes as all other human beings are at liberty to make' (An NHS Trust v P, 2013).

3.5 Part 2: Recurrent issues with collaborative working

During my fieldwork, my ongoing literature review shifted emphasis to consider the actual barriers that I was hearing described by participants, covered in the second part of this review.

3.5.1 Key barriers to effective collaborative working

The literature on collaborative working highlights many barriers to effectiveness. Whether the setting is primary care or secondary care, multi-agency teams or multi-agency working, formal partnership working or much more loosely affiliated working, children's services or adult services, the same issues are repeatedly highlighted in different contexts.

Reflective stop-off

As I began to familiarise myself with the literature, I started to keep a record of the issues that were being raised as barriers and facilitators to collaborative working in my reading. I began to reflect how interesting it was that study after study showed what could go wrong, but for practitioners there was so little to indicate how to put it right, how to do it better. Of course, this may be in part, as Kaehne (2017, p2) points out, because the goalposts for judging good integration are continually moving, owing to the constant state of flux in which agencies exist. Additionally, I noticed how few studies considered whether collaborative working had any impact on service users themselves. Much of the emphasis in the literature appeared to be on the process rather than the outcomes for service users. It seemed to me that unless the outcomes were improved, unless service users could say 'yes, it was better for me because you all worked together, and I could understand what you were all doing and why', then it was wasted effort. This process helped me to develop my initial research questions, and I re-visited and re-questioned the literature during the cycles of action research that I undertook.

Cameron et al (2014a) and Mackie & Darvill (2016) both focus on systematically reviewing UK literature on barriers and enablers to joint and integrated working in health and social care. In looking at factors that both promote and hinder integrated working, Cameron et al (2014a) review 46 papers, whilst the Mackie & Darvill (2016) review, which only looks at enabling factors, includes just 7 papers. This may indicate that there are many more barriers than facilitators to joint working. However, Mackie & Darvill (2016) have very narrow inclusion criteria, as they only consider papers which focus on adults with long-term conditions and include only studies carried out after 2006. Cameron et al (2014a) include papers which focus on older people and people with mental health problems, since 2000, which potentially gives them a much wider pool of papers to draw from. Nonetheless, taken together, the reviews show in essence that many of the barriers identified in the literature are the lack of, or the opposite of, the facilitating factors. Suggestions as to how to facilitate collaborative working are much less explored in the literature, and there are, as Cameron et al (2014a) say, a frustrating lack of comparative studies that have tried to put the facilitators into action. Key concepts in the literature on collaborative working are shown in Table 3.

Table 3: Key concepts in the literature

Key concept	Where identified
Agency 'buy-in'	Robinson & Cottrell, 2005; JIT, 2009; Abendstern et al, 2010
Service user involvement	Donnelly et al, 2013
Professional status	JIT, 2009; Robinson & Cottrell, 2005; Baker et al, 2011
Employment conditions	JIT, 2009
Stereotypes	Cameron & Lart, 2003
Organisational cultures	Cameron & Lart, 2003; Sloper, 2004; Ginsburg & Tregunno, 2005; Pinkney et al, 2008; Noga et al, 2016
Understandings of vulnerability	Stevens, 2013
Trust	JIT, 2009; Machura, 2014 ; Kim et al, 2016
Agency responsibilities	Machura, 2014; Tong et al, 2017
Staff morale and staff turnover	Sloper, 2004 ; JIT, 2009; Beaulieu et al, 2017;
Organisational structure and roles & responsibilities	Xyrichis & Lowton, 2008; JIT, 2009; Stevens, 2013 ; Jolanki et al, 2017
Priorities	Robinson & Cottrell, 2005; Machura, 2014
Information sharing	Robinson & Cottrell, 2005; JIT, 2009; Pinkney et al, 2008; Abendstern et al, 2010; Stevens, 2013; Cameron et al, 2014a; Machura, 2014; Jolanki et al, 2017; Beaulieu et al, 2017; Waring et al, 2018
Resource distribution	Cameron & Lart, 2003
Power differences	Robinson & Cottrell, 2005; Pinkney et al, 2008; Baker et al, 2011; Thistlethwaite et al, 2013; Kim et al, 2015; Ambrose-Miller & Ashcroft, 2016;
Lack of resources	Cameron & Lart, 2003 ; Sloper, 2004; Kim et al, 2016; Tong et al, 2017
Communication	Cameron & Lart, 2003; Reder & Duncan, 2003; Sloper, 2004; Suter et al, 2009; Stevens, 2013; Ambrose-Miller & Ashcroft, 2016; Kim et al, 2016; Mackie & Darvill, 2016
Role definition	Kim et al, 2015; Kim et al, 2017; MacDonald et al, 2010; Sloper, 2004, JIT, 2009
Knowledge of the professional role of others	Cameron & Lart, 2003; Pinkney 2008; Suter et al, 2009; MacDonald et al, 2010; Stevens, 2013; Cameron et al, 2014a; Ambrose-Miller & Ashcroft, 2016; Beaulieu et al, 2017; Sprung & Harness, 2017
Priorities	Cameron & Lart, 2003 ; Manthorpe et al, 2010; Pinkney et al, 2008; Cameron et al, 2014 ; Machura, 2014
Conflict and mechanisms to address it	JIT, 2009; MacDonald et al, 2010; Brown, 2011; Machura, 2014; Kim et al, 2015; Kim et al 2016; Sexton & Orchard, 2016; Kim et al, 2017; Leigh, 2017

Based on the aims of this research, and issues which were emerging during the diagnostic phase it became clear that there were several areas which were being repeatedly highlighted as barriers, which will be considered in more detail here. These were,

- Communication
- Information sharing
- Understanding of other professionals roles and responsibilities
- Power and status differences between professional groups
- Conflict

3.5.2 Communication

Good communication is considered the 'bedrock of successful inter-agency working' (Cameron & Lart, 2003, p12). Yet poor communication is regularly cited in SAR's as a reason for the failure to protect vulnerable adults (Stevens, 2013). It is frequently highlighted in the literature as a cause of difficulty in multi-agency working (see Table 3 above). However, 'communication' is a very wide ranging, poorly defined term, with meanings that vary according to context and individual (Barr, 2013). I will focus here on two aspects of communication, which dominate the literature; shared language, and information sharing.

3.5.3 Lack of a shared language in multi-agency working

Suter et al (2009), undertook a large qualitative study in Canada looking at what competencies front-line practitioners believed were most important for good collaborative practice. They found that effective communication was identified as one of the two core competencies. Various communication skills were mentioned by participants, one of which was the ability to 'adjust the language to the target audience' (p46) whether this was in relation to the service user or to other professionals. Good communication was felt to be key in resolving conflict and improving patient outcomes. However, Morris (2008) is clear in the belief that there does not appear to be a common language used in multi-disciplinary work, and sees this as evidenced by the lack of consensus around describing shared work activity. A risk inherent in this is that definitions of concepts such as abuse and vulnerability become ‘woolly’ (Aylett, 2016, p35).

Machura (2014) carried out a quantitative study looking at inter agency co-operation in children’s services across two local authorities. Participants’ professions were not asked for, as the author argues this would have threatened anonymity, but this does mean the study is weakened somewhat. However, participants were asked whether agencies involved used common terminology. Only 6% of the 210 respondents answered that they always did, and 35% said they only sometimes did. Although it is impossible to know what the participants understood by ‘common terminology’, these are nonetheless disappointing figures – although, frustratingly, Machura offers no further discussion or analysis of them. McDermott (2010) found that semantic distinctions were important because different professionals made different judgments about risk according to their definitions. Scourfield (2010), questions the meaning of the term ‘lifestyle choice’ commonly used by professionals to describe the situation of people living in squalor.

Practitioners may use ways around this. One is to use many different terms to describe the same person or situation – service user, patient, client, etc. (McLaughlin, 2009). Another, in predominantly medical majority teams, which also include social care, is to adopt the language of the medical model (Aylett, 2016).

Sheehan et al (2007) in a fascinating study in which principles of symbolic interactionism were used to analyse data from interviews with both inter-professional and multidisciplinary teams, found that the former used more inclusive language than the latter, where although members worked in parallel, they did not share a common understanding. Significantly, the study found that being able to use inclusive language facilitated conflict resolution. Similarly, as Suter et al (2009) found, good communication was necessary not just to co-ordinate care and use appropriate language, but to negotiate and resolve conflict. Communication encompassed the ability to negotiate and resolve conflict as well as co-ordinate care and use language appropriate to the target audience (ibid, 2009). Edwards (2004) argues that professionals need to become 'multilingual' (p7) in order to be able to understand and respect the linguistic constructions used by other professionals' and the meanings they are intended to convey within that particular profession. This is well demonstrated by a hospital social worker in an integrated team, interviewed in *The Guardian*,

> Early on, there was a cultural issue about social workers and clinicians working differently. We had to learn each other's language. It was an issue we had to explicitly address (Andalo, 2016, np).

Kaehne (2018) posits that on a more structural level, language that is used about integration tends to make the tacit assumption that there is a 'reservoir of shared values which transcend sectoral or organisational interests' (p164), but believes that this utopian vision is bound to fail.

3.5.4 Information sharing

Effective information sharing in multi-agency working is highlighted as being extremely important but, in practice, is a 'key procedural fault line' (Robinson & Cottrell, 2005, p555) where cracks occur (JIT, 2009; Abendstern et al, 2010; Machura, 2014; Jolanki et al, 2017). A report from the Care Quality Commission in 2018 identified serious flaws in the exchange of information between hospitals and social care providers for older people on discharge from hospital, with the problem being particularly acute for domiciliary care providers, who were not given key information that they needed to care for the person. Stevens (2013) suggests that one of the reasons for these problems may be uncertainty over the demands of the Data Protection Act 2007, which leave practitioners with a lack of confidence about sharing information. This may now be compounded by the introduction of the General Data Protection Regulation in 2018 and the Health and Social

Care (Safety and Quality) Act 2015 which introduces a new legal duty requiring health and adult social care bodies to share information where this will facilitate care for an individual. These difficulties may be particularly acute in situations of crisis and emergency, where ad hoc teams have little experience of working together (Waring et al, 2018). On a practical level, the lack of shared computer systems is often highlighted (Stevens, 2013; Maguire et al, 2018) yet efforts to change this have been prone to failure (Maguire et al, 2018).

There is perhaps another perspective to consider here. This is the assumption that sharing private, sensitive, confidential information across multiple agencies *should* be easy. Peters (2001) sees the development of information sharing and the new information systems as a 'shift toward an increase in policing and surveillance by the state' (p61). He describes this relationship between government and knowledge as one where information sharing effectively increases surveillance on individuals. Grace (2015) suggests that the enthusiasm for better information sharing between agencies could actually result in safeguarding decisions that do not respect the due process of the law. Lastly, Robinson & Cottrell (2005) question whether service users realise the considerable implications when they give consent for agencies to share information across numerous boundaries.

3.5.5 Lack of understanding of other professional's roles and responsibilities

Understanding and appreciating professional roles and responsibilities is a core competency for collaborative practice (Suter et al, 2009). However, this pre-supposes that professionals are able to define clearly their own roles, which Morriss (2016) argues, with increased role blurring, may not be the case. Dickinson (2006) found that lack of understanding of roles led to confusion and protectionism in attempts to implement a single assessment process, and concerns about role blurring.

Studies of inter-professional education (MacDonald et al, 2010) identify that this lack of role understanding is already present in pre-qualifying students from all professions, and continues well beyond qualification, which, becoming entrenched can result in stereotyping, conflict, and poorer outcomes for service users (Hall, 2005; Brown et al, 2011). Better outcomes *may* perhaps be achieved if better role understanding can be achieved and 'turf wars and duplication of care are avoided' (Suter et al, 2009, p49), but there is little evidence for this (Cameron, 2016).

A recent inspection report from the SCIE, looking at problems with implementation of the Care Act within a local authority in the UK, recommended that staff needed more understanding of each other's roles 'to enable a better join between health and social care at frontline level' (SCIE, 2016). It found that social services staff reported that health staff were 'helpful' (p14) when asked for information but resisted joint working. The report called for practice-sharing opportunities across health and social care, to 'promote consistency, mutual understanding and maximise learning and support' (p29). Glasby and Miller (2015) in a literature review looking at relationships between social care and general practice, note that the relationship between social workers and GP's has been reported as poor, with lack of understanding of roles compounded by 'lack of meaningful contact with each other' (p43) and differences in employment status (salaried social workers versus self-employed GP's). It is difficult, however, to know what 'meaningful contact' (ibid) might entail, or how 'practice-sharing opportunities' (SCIE, 2016) might be designed. In Cameron's (2016) self-review of two earlier literature reviews of joint working (Cameron et al, 2003; 2014a), the author suggests that whilst entrenched differences in culture, philosophies and values prevail, joint working will be undermined. She argues that not only does role understanding between professional groups needs to occur on a strategic level as well as at practitioner level, but also that government, professional bodies and educational providers need to provide opportunities for professionals to build a shared understanding of the importance of collaborative working.

3.5.6 Power differences between professional groups

Another problematic area frequently mentioned in the literature is differences of power and status in inter-professional working situations (JIT, 2009; Kaehne, 2018). Lukes' (1974) influential study of power suggested that power has three dimensions or faces. The first is decision making power, which can be described as the ability to choose issues and outcomes. Lukes argues that behind this visible aspect of power, lies 'closed face' or non-decision making power, that is, the ability to decide which issues are deemed important to deal with, and which are not, and to shape the agenda. Thirdly, Lukes defined a wider form of power, that of insidious or manipulating power, whereby there is domination of one over another, but, importantly those who are dominated acquiesce to being dominated (Dowding, 2006). Lukes' work has been extended to include the forms, spaces and levels of power (Gaventa, 2006). In terms of the forms of power (similar to the original three faces of Lukes) these are 'visible', 'hidden' and 'invisible' (Hathaway, 2016, p120). Hidden power can be seen as particularly important in multi-agency working, involving as it does 'the manipulation that occurs behind the scenes' (ibid) which may serve to exclude weaker actors from decision making procedures, such as important meetings or informal contact.

In their seminal work, French and Raven (1959) propose five forms of power relevant in the workplace, to which Raven (1965) later added another. These are,

- Legitimate power – where a person is believed to have the right to make demands and expect compliance
- Reward power – where a person is able to reward another for compliance, for example in distribution of work, or training opportunities
- Expert power – where a person has a high level of skills and knowledge
- Referent power - power which results from a person being liked and respected
- Coercive power – where a person is believed to have to have the ability to punish others for non-compliance
- Informational power – a person's ability to control access to the information that others need

These ideas are very useful in considering where power lies in multi-agency working. Models of collaborative working in community settings have tended to have medical staff such as GP's and psychiatrists as the dominant professional (Thistlethwaite et al, 2013), with a high level of expert power, which may be difficult for others to challenge. The pathologising of self-neglect as a mental illness (APA, 2013) increases this power, as this becomes the dominant discourse. Informational power may be particularly important in relation to the difficulties associated with information sharing discussed above (Robinson & Cottrell, 2005).

Kim et al (2015) analysed diaries kept by nurses over a six month period, to examine their perceptions of conflict. These showed that that power differences managed through poor communication were perceived by the nurses to cause damaging conflict. Power is closely allied with professional status, and Robinson & Cottrell (2005) identified that different professionals might set a different value on status differences. This is an interesting mixed methods study consisting of observations, interviews, analysis of diaries and focus groups with various professionals working in children's services. Although it is a large study covering five teams, the teams are very diverse, including a youth crime team and a neuro-rehabilitation team, and whether the findings could be extrapolated to adult services is unknown. However, one of the themes they identify was that of power and status amongst team members, and note that differences can cause tension. Interestingly, a psychologist (high status, high expert power) quoted in the study, eschewed any knowledge of status issues, whereas the social worker (lower status, low expert power) was very pre-occupied with them, though insisting she was not 'overawed' by the consultants. There were also status differences in teams where the majority of professionals were employed by one agency, and the minority employed by another. A danger was identified that the minority, often part-time or seconded, were seen as peripheral to the core team.

If there are power and status differences inter-team, there are also differences inter-organisation, so called 'turf battles' (Sheehan, 2007, p18). The loosely affiliated team group of professionals working with people who self-neglect (and working together in safeguarding more generally) may well be dominated by public sector employees who carry legal and policy responsibilities. In a comment piece, Thomas (2015), who works for a private sector housing association notes that ‘integration is often limited in thinking and action to “public sector” integration’ (2015, p194). Thomas states her belief that the public sector has always been viewed as the superior provider of housing services and of a higher status. Thomas describes being at a meeting where local authority officers were welcomed as ‘colleagues’ and those from the independent sector as ‘friends’ (p198). She notes that ‘Foucault argues that this is classed as ‘othering’ and is a show of strength and hierarchy and keeps the power where it already lies’ (p198).

A report from the Joint Improvement Team (2009) suggests that the democratic decision making required for collaborative working between agencies such as social care, health and housing represents a threat to professional status and control (JIT, 2009). Addressing the differences of power and status between the public sector and the private and voluntary sector are crucial for successful multi-agency working, but are little discussed in the literature.

3.5.7 Conflict in collaborative working

Tjosvold (1998, p287) defines conflict as ‘opposing interests involving scarce resources and goal divergence and frustration’. Conflict is frequently described in the literature on collaborative working, although the majority of studies focus on tertiary settings rather than primary care or community settings (Brown et al, 2011). This is reinforced by an integrative review by Almost et al (2016) of literature, with 44 papers included, on sources, causes and predictors of conflict in healthcare teams. This review found that sources of conflict included role ambiguity and poor communication (as discussed above in relation to this study). However, few published studies of interventions to mitigate or manage conflict were found, and those that were, tended to be reported as weak. Likewise, Sexton & Orchard (2016) found few studies which focused on developing practitioners' problem-solving skills and ability to resolve conflicts. Yet having effective conflict resolution mechanisms between agencies seemed to enhance co-operation (Machura, 2014).

Tjosvold (1998) argued that conflict could be positive, and posited the notion of 'co-operative conflict', the benefits of which could include organisational change, increased morale and better awareness of each other. However, this is not, largely, reflected in the literature on conflict in collaborative working, although Lauder et al (2005c) suggested there could be a more 'therapeutic' role for professional groups if they could begin to have a better appreciation of their differing approaches to self-neglect.

If staff do not feel confident in their professional roles, and if they do not understand the roles of others, they will not feel safe enough to work together effectively. This will result in conflict, to the detriment of both team members and service users (Laidler, 1991). Watts & Jones (2000) argue that conflict in collaborative working is likely because of the deep rooted differences between professional groups, located in their different knowledge base, enculturation, socialisation and training. Brown et al (2011) describe conflict as inevitable, at both the micro and meso levels, for example, over new practice guidance or numbers of patients.

In their comprehensive phenomenological study of a range of health professionals, which in fact included a significant number of non-health staff, including social workers, they identify barriers to conflict resolution, including lack of time and heavy workloads; people in less powerful positions feeling resentful or being silenced; lack of recognition of conflict and unwillingness to address it; and a tendency to avoid confrontation rather than upset people (ibid). Brown et al (2011) suggest that where a patient represents a 'wicked' problem (a patient with a complex set of symptoms or complex biopsychosocial issues), this may necessitate multiple interventions which can create conflict if the professionals involved do not agree. Kim et al (2016) suggest there are two ways of conceptualising conflict, as task-based (for example workflow or policy compliance) which tend to lack an 'emotional undertone' (p256), and relationship-based (personality friction, different norms and values) which can result in blame and disrespect. Both of these perspectives are relevant to multi-agency working with people who self-neglect.

Kane (1975) argues that conflict in inter-professional teamwork may be as much explained by group process considerations as by the interaction of professional roles and status. Allport's seminal Contact Hypothesis (1954) suggests that contact between 'in' and 'out' groups, (such as Thomas describes above), will reduce prejudice and stereotypes held by and between groups. However, there are important conditions to be met. Groups must be of equal status, there must be inter-group co-operation towards a shared goal, which can only be attained *by* working together, and the intergroup contact must be explicitly supported by the institutions involved (Allport, 1954). Michaelec et al (2017) have recently refreshed Allport's work, in a quantitative, questionnaire based study of 528 students on an interprofessional education programme. Their findings showed that simple opportunities for informal interaction and socialisation may have had significant impact on the student's perceptions of each other's role and were highly valued by them. Where practitioners are unsure of each other's roles and responsibilities, as discussed above, expanding their knowledge in an informal setting may have implications for the lessening of conflict. However, as McNeil et al (2013) note, where interprofessional anxiety is high, bringing people together may simply increase polarisation and conflict.

3.6 How could collaborative working be improved?

As argued above, the literature on collaborative or 'co-operative' working is under-theorised (Reeves & Hean, 2013; Reeves et al, 2017; Auschra, 2018). Suter et al (2013), attempt to remedy this by suggesting a list of theories that could potentially be used to inform practice. This is an interesting approach, though they do not provide any suggestions for practical application, and it does not allow for the emergence of new theoretical approaches. Galpin & Hughes (2011), in a discussion paper on safeguarding and personalisation, identify a need for effective practice in multi-agency decision-making to be able to deliver support that both empowers and protects, and call for a structured model for decision making across agencies. They propose the use of the Harvard Business Model (ibid, p152), with an additional action planning stage 'added on'. Their rationale for choosing this model is not transparent, and in many ways it seems an odd choice to apply a business model to organisations which are not 'businesses' in the traditional sense, though it would be consistent with a New Public Management approach whereby private business practices are applied to the public sector and non-businesses (Crouch, 2011). However, Kaehne (2017) argues that 'integration is not a scientific theory' (p4) or a 'mature scientific paradigm' (p8), it is a practice, a policy formulation and an object of study, founded on 'an aspirational belief … sustained by a normatively charged vocabulary' (p8).

Dickinson (2014) argues that two perspectives are found in the literature, the predominant one of integration as a science, and the subsidiary perspective of integration as 'craft and graft' (p190). Integration as science aims to isolate specific factors that facilitate integration, in order that these can be replicated in other contexts. For example, a literature review by Gonzales-Ortiz et al (2018) focusses on factors which influence the success of care integration, with the purpose of developing a comprehensive framework for implementation. Comprising 18 studies, from an initial 710 screened, the review identifies 12 domains, comprised of 175 items which are felt to influence the success of care integration. However, Dickinson (2014) argues that this is the wrong focus, and that it may be more fruitful to focus on a 'craft and graft perspective' (p192) which is less interested in the mechanisms that make integration work and more on the working practices of those involved and views context and local practice as crucial. She argues that what is important is the 'actual practice of integration' (p192). However, this focus may prove more difficult than it sounds, as collaborative working is also seen as poorly evidenced (Redding, 2013; Dickinson, 2014; South et al, 2014; Kaehne, 2017).

Literature reviews by Cameron (Cameron & Lart, 2003; Cameron et al, 2014a) identify a preponderance of outcome studies and evaluations but a lack of large-scale comparative studies in the area of joint working. Fraser (2019) notes that while many evaluations of integrated working initiatives have been published it is rare to find studies that have a comparative design or pre- and post- intervention analysis. Kaba et al (2016) found that where a pre/post study design is used, it is habitually without a control group. Gonzalez-Ortiz et al (2018), found that many studies took place in specific contexts or with clearly defined target groups, usually patients with chronic illnesses, rather than wider health and social care needs, and that,

> Few studies propose, and eventually validate, frameworks indicating key areas of intervention and/or analytical aspects to consider in order to foster care integration. They are mostly lists of key building blocks to integrated care, rather than frameworks supporting the process of implementation (p10).

Perhaps this is because, as Glasby (2013) suggests 'There's no 'one size fits all' solution – if there was, we would have found it by now' (np). There are two issues at the heart of whether there is or is not a 'solution'. One is that this debate does not help practitioners in any way. Whilst they are being directed to work co-operatively by policy and legislation (such as the Care Act duty to co-operate in safeguarding cases) even the official guidance gives little advice about how to do so effectively,

> Different areas are likely to find success in different models. Whilst some areas may pursue for (sic) integrated organisational structures, or shared funding arrangements, others may join up teams of frontline professionals to promote multi-disciplinary working' (Care Act Guidance, 2016, s15.11).

McCreadie et al (2008) posit that a lack of prescriptiveness about how to implement safeguarding policy adheres to Matland's (1995) ambiguity-conflict model of policy implementation (Table 4, below). Matland argues that the key considerations in implementing policy are ambiguity and conflict. McCreadie et al (2008) argue that safeguarding policy is of the high ambiguity/low conflict type, which causes uncertainty amongst staff. However, it is difficult to see why they characterise such policy implementation as low conflict, when in their findings they uncover ‘a number of areas of conflict’ (p248), and they do not adequately explain this apparent inconsistency.

Table 4: Matland's ambiguity-conflict model of policy implementation. Adapted from Matland (1995, p145)

High conflict/low ambiguity (political implementation)	High conflict/high ambiguity (symbolic implementation)
Low conflict/low ambiguity (administrative implementation)	Low conflict/high ambiguity (experimental implementation)

3.7 Does collaborative working improve outcomes for service users?

The other issue in relation to a ‘solution’, is that the benefit of collaboration for the patient or service user is not clear, and that ‘integration remains an inter-professional endeavour, not a patient orientated one (Kahne, 2017, p3). Dickinson & Glasby (2010), in their study of a merger between two mental health trusts, found that desired outcomes identified by staff were primarily organisational rather than service-user focussed, and were unlikely to lead to better outcomes for them. This was a mixed methods study, using questionnaires and interviews, and frustratingly little detail is given of the statistical analysis of the questionnaires. However, in a later article, Glasby (2017) argues that integrated care can ‘sometimes improve patient experience and make services more patient centred’ (p1). To this rather cautious optimism he adds that at the very least, ‘unintegrated care typically doesn’t [work]’ (ibid). However, he offers no evidence for this assertion. It could be concluded that in terms of improving outcomes for service users, there is little compelling evidence that integrated care either does or doesn’t work, and neither the ‘craft’ nor ‘graft’ perspectives (Dickinson, 2014) contribute greatly towards achieving this. Indeed, McCreadie et al (2008) found that the distractions of trying to follow multi-agency procedures, practitioners ‘lost sight of the outcomes’ (p256) for service users.

Morris (2008, p1) describes multi-agency working as a ‘skillful and challenging activity’ that can either enhance the experience of those using services or cause it to be frustrating and disempowering. Its value, Morris believes ‘lies in being able to respond holistically to needs and arriving at broader understandings of causes and possible responses’ (p173). Morris stresses that multi-agency working is not about diluting the skills of individual workers, termed ‘creeping genericism’ by Jasper et al (2016), but rather in recognising and utilising the skills and knowledge that each professional brings. Both Morris (2008) and Sloper (2004) argue the importance of articulating and facilitating the intended outcomes of multi-agency working. Sloper (ibid) argues the need for research to support this aim, as there is little evidence of the effectiveness of multi-agency working in improving outcomes for service users. Quinney & Hafford-Letchfield (2012) argue that there is no body of research evidence to show how working together leads to more effective and safer practice.

It is argued that there has been an emphasis on the process of collaborative working to the detriment of improving outcomes for the service user (Pinkney et al, 2008; Redding, 2013) and evidence for impacts on service users is sparse (Atkinson et al, 2007; Cameron et al, 2014b; Kaba et al, 2016; Glasby, 2017). Kaehne (2017) argues that the main driver behind health and social care integration has been a drive towards professional standardisation rather than patient care, and Petch et al (2005) suggest that there is only a tentative connection between the outcomes that service users want and the extent to which partnership policies reflect this. A study by the organisation National Voices (Redding, 2013) found that features particularly identified by service users as important were continuity of staff and sufficient staff, and a good range of resources.

3.8 Collaborative working with people who self-neglect

There is little in the literature that explores the situation of self-neglecters, who may find themselves part of a complex multi-agency intervention. Different agencies will be drawn in to carry out different assessments and co-ordinate different aspects of a person's support, and the service user is highly unlikely to have one point of contact. Braye et al (2013) note that there was no systematic way of allocating self-neglect work to the different professional groups in any local authority taking part in their study. Under these circumstances, the experience of multi-agency working for the service user has the potential to be far more oppressive. Lauder et al (2005c) found that service users with a formal psychiatric diagnosis appeared to have the widest multi-agency support networks, whereas those with no formal mental health diagnosis were seen as those for whom self-neglect was a lifestyle choice, and were more likely to be subject to 'enforcing interventions'(p322) by agencies.

3.9 Does collaborative working threaten people who self-neglect?

In the previous chapter I explored the self-neglecting person through the neoliberal gaze, and Singh & Cowden (2015) suggest that when people are viewed as having failed to empower themselves, professional interventions, often punitive, are legitimated. When professionals are working in concert, the power ranged against the service user is considerable. Considering this perspective it is useful to draw on Foucault's (1991) notion of discipline. He argues that there are three instruments of discipline, hierarchical observation, normalising judgement and the examination. Hierarchical observation makes individuals highly visible and keeps them under watch (Foucault, 1991; Schwan & Shapiro, 2011) and this is exactly what a multi-agency team are able to do to the self-neglecting service user. Their many pairs of powerful eyes can keep the service user under observation much more effectively than one pair of eyes working alone, a type of reverse panopticism (Foucault, 1991), comprising the ‘institutional gaze’ within the service user’s own home. Service users are watched and evaluated (normalising judgement) ‘not only for what [they] do that may break the rules but also for how [they] fail to achieve a certain standard’ (Schwan & Shapiro, 2011, p118) and discussed at multi-agency case conferences at which they will probably not be present. The examination (Foucault, 1991) combines both normalising judgement and hierarchical observation, and ‘establishes over individuals a visibility through which one differentiates and judges them’ (p184). It makes each individual a ‘case’ (ibid, p191). The service user can thus be set up to fail because it is hard for them to see what the standard is to which they should be conforming, as professionals may define it differently.

Group processes may also play a role in threatening service user autonomy. Moscovici & Zavalloni (1969) identified the ‘group polarisation effect’ which occurs when people assess risks as part of a group, whereby they are likely to make harsher judgements than if they had made the assessment alone. If one person in a group assesses a risk as severe, then others will be reluctant to contradict them, fearing that they have overlooked something. As a result of this agreement, the first assessor will re-appraise their original assessment more harshly to preserve the validity of their view (Abrams et al, 1990; Bee, 2016). Further agreement by the group will raise the bar still higher, ad infinitum. Allied to the group polarisation effect is the concept of ‘groupthink’, proposed by Janis (1982), whereby the desire for conformity, unanimity and conflict minimisation will cause groups to reach decisions without critical evaluation of alternatives, and by the suppression of dissent. Decisions that are made may consequently be irrational and highly political (Ginsburg & Tregunno, 2005), depending on factors such as how problems are framed, and individual accountability. However, Tjosvold (1998) argues that conversely, such negative outcomes are not a given, and there could be situations where approaching conflict co-operatively would produce better results, in this case, for the service user who is the subject of these group processes. An essay by Kaba et al (2016) argues that groupthink continues to be a risk in multi-disciplinary care interventions, which can cause poorer decisions to be made.

3.10 Conclusion and gaps in the knowledge

Many different agencies may be involved in the life of a self-neglecting person, and it is important that these agencies are able to work together, with shared aims, purpose and understanding. However, it is apparent from a review of literature in this area that all too often no such consensus exists, and that agencies struggle to work together in this area to produce positive outcomes. Braye et al's scoping study of workforce development (2013) found no literature on self-neglect in relation to the workforce published since 2009. The authors note that the omission 'stands in contrast to the emphasis that much of the literature places on partnership' (p13). As the literature review demonstrates, many studies focus on only one or two professional groups, feature senior management rather than practitioners, and are from outside the UK, or do not take account of the development of the English legal framework.

Lauder et al (*2*005b) write that the starting point for intervention must be an explicit and agreed framework for good practice, particularly because of the lack of evidence-based interventions in this area. This included the need for agencies to be better informed about each other's potential remits, and the need for better training and support. More than a decade later no such framework yet exists in practice in England, and there appears to be no clear understanding of how professionals can work effectively together in this area. Whilst the literature is useful in identifying the challenges for practitioners, it does not offer much to give direction to them. In workshops held as part of Braye et al*'s* study (2011a) it was noted that professional uncertainty about self-neglect causation, and what interventions to pursue, made the writing of policies and procedures challenging.

No recent studies were identified which compared or explored the understandings and responses of the wide spectrum of different agencies working with self-neglect. Braye et al (2013; 2014a) identify a need to develop training and practice development mechanisms to facilitate creative practice, and inter-agency systems for shared assessment, intervention, risk management and decision-making. RiPfA (2013) highlights the need for agencies to have opportunities to discuss and reflect on perceptions and values around self-neglect, and to develop a shared language. It notes that different professional groups will have different approaches and may have little understanding of the roles of other professionals. They argue that will make it difficult to achieve a co-ordinated approach.

Few studies were identified which looked at what defines successful multi-agency interventions in self-neglect. The objectives of any form of intervention described in the literature are seldom made explicit (Lauder et al, 2005a), and Braye et al (2011a, 2013) found uncertainty about what causes self-neglect and what course of action to take – described by one participant as ‘a foggy mass of mess’ (Braye et al, 2011a, p183). Braye et al (2013, p21) note that ‘there is a pressing need for outcome studies to provide further data on ‘what works’ with self-neglect’.

In this chapter I have reviewed the literature on collaborative working in relation to the situation in the UK, and with specific emphasis on working with people who self-neglect. I have also considered the key areas of difficulty identified in the literature around multi-agency working. Figure 2 shows the conceptual framework guiding this research. Maxwell (2013, p44) argues that there are four chief sources that the researcher should drawn upon to construct a conceptual framework. These are a synthesis of experiential knowledge, existing theory and research, pilot and exploratory research, and thought experiments. The opening chapter introduced my experiential knowledge and this chapter has reviewed existing theory and research. In subsequent chapters I will discuss my pilot research and explore further the experiential knowledge and thought experiments which have had an impact on the research. The next chapter describes the methodology I have employed in this research, which is shown as part of the conceptual framework.

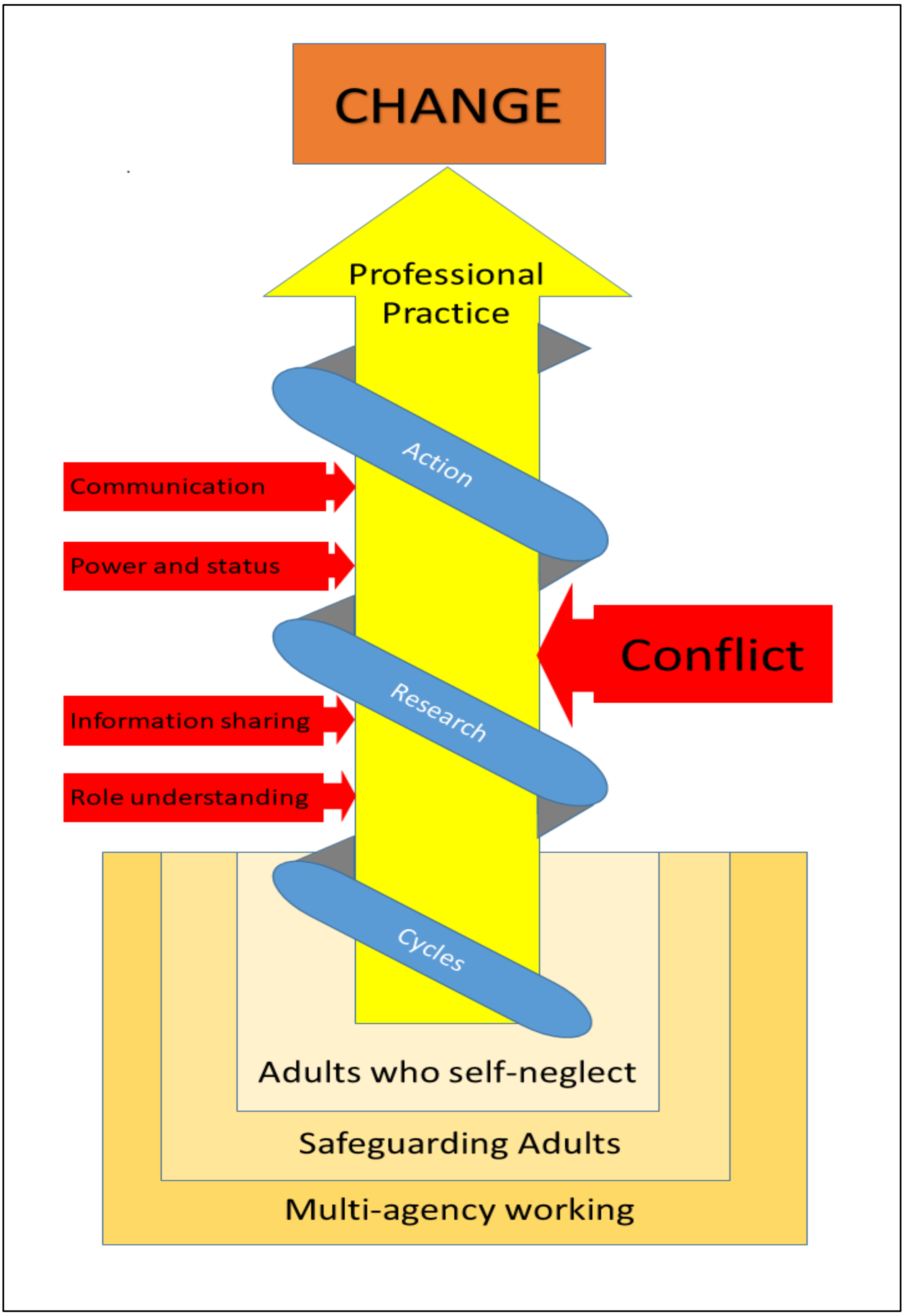


Figure 2: Conceptual framework for this research

Chapter 4 – Research methodology

4.1 Introduction

In this chapter I will discuss my reasons for using an action research (AR) approach to explore multi-agency working and self-neglect. I will discuss the origins and development of AR and the reasons for choosing the specific model of 'professionalising action research' (Hart & Bond, 1995) to underpin this study. I will consider to what extent this research can be considered to be located within a participatory paradigm. The terminological and methodological uncertainty surrounding AR can make it difficult to define the parameters within which, as a researcher, one is working, and it is therefore important to consider the theoretical concepts that can be said to underpin and inform AR, and to locate it within its wider context. To do this, I will discuss the influence of social constructionism and pragmatism on AR and the relationship between the three.

4.2 Why Action Research?

I have utilised an AR approach in this study, because 'it is a powerful tool for change and improvement at the local level' (Cohen et al, 2000, p226), and is appropriate where 'a problem involving people, tasks and procedures cries out for a solution' (p334). I felt that an action research study was apposite because the two main concerns of my research, self-neglect, and multi-agency working, were both 'ill-defined and deeply rooted, complex, specialist and intangible' (Ritchie & Lewis, 2003, p32), and emergent (Gray, 2014; Stuart, 2012). They combine to form the 'wicked mess' (Hancock, 2010, p xiii) described earlier.

AR can also be viewed as being key to bridging the gap between theory and practice (McVicar et al, 2012), with reflection leading to action and action informing reflection. Having observed as a practitioner how the 'high hard ground of theory' seemed to have little impact upon the 'swampy lowland of messy, confusing problems' (Schön, 1987, p1), it was important for me to undertake research in a way that tried to bridge that gap, and which offered the possibility of giving something back to the people who participated in the study (Herr & Anderson, 2015). Over time, the process of the research and the relationships between all stakeholders became as important as substantive findings or any potential solutions to the 'problem' (Bryman 1989).

4.3 What defines Action Research?

Definitions of AR abound (see, for example, Carr & Kemmis, 1986; Reason & Bradbury, 2006; Stringer, 2014). As Dick (2015, p433) notes,

> In 1993 Elden & Chisholm were able to talk about the many varieties of action research. Ten years later Chandler & Torbert (2003) could identify '27 flavours', as they called them. Nearly a decade later again, Raelin (2011) could identify a similar variety in what he labelled 'action modalities'.

Dick concludes therefore, that action research is a 'large family of diverse methods' (p432), which, as Greenwood (2015) describes, may be used strategically by the action researcher.

There is also debate about whether AR can be considered a methodology. For Crotty, writing in 1998, AR is a methodology located in a tradition of critical enquiry. However, thirty years later, Herr & Anderson (2015) note that many researchers see AR instead as an 'orientation or stance towards the research process and participants' (p1). This may be because, as Reason (2003) contends, '[AR] has different purposes, is based in different relationships, and has different ways of conceiving knowledge and its relation to practice' (p106). Dick (2015, p432) takes this further when he says that 'the present custom … is to claim that AR is not a methodology'. However, Attwater (2014) argues that AR is increasingly being seen as a meta-methodology, which allows for different positions of epistemology and discipline, and that this is what gives it its strength, however many 'flavours' there may be.

However, for many positivists, AR suffers a credibility problem. Greenwood (2015) believes that AR is often seen as 'just a group of 'do-gooders' telling nice idiosyncratic stories of no scientific value' p205). Of course, this is rebutted at every turn. For example Gergen & Thatchenkery (2004) argue that if postmodernism has invalidated pure positivist research, nothing has replaced it, and that perhaps AR helps answer the question of how to proceed. Greenwood (2012) notes that though AR uses a variety of methods and outcomes, it does so 'opportunistically' (p121) and eclectically, as discussed above in relation to its theoretical base, and whilst this can be seen as a strength, it is this that makes it vulnerable to challenge, because it doesn't easily fit 'within an established box' (p121).

4.4 The Foundations of Action Research

> There is nothing so practical as a good theory (Lewin, 1951, p169)

Inspired partly by the pragmatist Dewey's work on thinking and learning from experience (Dick, 2015), Lewin first used the term 'action research' in the 1940's, which he described as, 'a comparative research on the conditions and effects of various forms of social action and research leading to social action' (Lewin, 1946, p35). Lewin believed that theorists should try to find new ways of conceptualising and understanding problems, to enable them to respond differently (Ash, 2014). He also believed that knowledge without practical outcomes was inadequate, 'Research that produces nothing but books will not suffice' (Lewin, 1946, p35).

Lewin (1946) proposed a model for social research that 'proceeds in a spiral of steps, each of which is composed of a circle of planning, action and fact-finding about the result of the action' (p38). Lewin's model has been modified over time, but all versions represent a cyclical process of 'learning about practice, making plans to change practice based on the learning, implementing these changes and evaluating the success of these changes' (Spalding, 2009) – the 'plan, act, observe, reflect' cycle. Winter & Munn-Giddings (2001) criticise the spiral framework for oversimplifying a complex process, implying that AR must take place over a long time period, and being hard to distinguish from everyday interactions. Nonetheless it remains influential. In addition to his work on AR, Lewin also developed a highly influential model of planned organisation change, still widely used today (Senior & Swailes, 2016). My overall research plan was based on the Lewinian 'spiral' (Lewin, 1946) and in Chapter 8 I discuss the synthesis of action research with Lewin's (1951) model of change management.

However, as Dick (2015) points out, actual AR studies are 'rarely as neat as this spiral of self-contained cycles' (p439). Instead there is an emergent process as the AR project develops, deeper understanding is achieved and practice is improved (Dick, 2015). Perhaps, as Cook (1998) writes, some 'mess' or 'spontaneous creativity' in AR is both inevitable and desirable. This will be explored further in subsequent chapters.

4.5 What are the key characteristics of Action Research?

Although the many manifestations of AR have been noted above, AR can be considered to have key distinguishing features:

- It is designed to bring about change (Bogland & Bikland, 2007: McIntosh, 2010; Dick, 2015). AR involves, to a greater or lesser extent, participating in a situation of change, designed to find a new course of action that brings about improvements, whatever the context. This challenge to the status quo is important because social institutions are characterised by 'dynamic conservatism' (Schön, 1987), which constantly 'pulls practitioners back to a status quo that consists of norms, rules, skills and values that become so omnipresent as to be taken for granted and go unchallenged' (Herr & Anderson, 2015, p28). In social constructionist terms, AR tries to change the dominant discourse. Associated with the change, in certain contexts, may be the aim of increasing social justice (Carr & Kemmis,1986; Herr & Anderson, 2015). The research will differ in each case, in terms of the scale, scope and aims of the change.

- AR values the knowledge and wisdom of its participants. Both Greenwood (2015) and Eikeland (2008; 2015) relate this to the distinctions drawn by Aristotle in the Nicomachean Ethics, between different kinds of knowing. These include *epistēmē* (deduction, predictive modelling), *techne* (expert technical knowledge) and *phronēsis,* which can translate as prudence, or more usually as practical wisdom. Although as Greenwood notes (2015), Aristotle's distinctions have become part of the discourse of AR, it is *phronēsis* that is the central concept (Eikeland, 2015). This is because of 'co-generative knowledge and action development processes and because of the shared authority between the researcher and the stakeholders' (Greenwood, 2015, p208) which characterise AR. Greenwood (2015) believes that ontological positions, the relationship between the knower and the known, are fundamental to AR because of the knowledge the knowers possess and bring to the research. This 'native, practitioner knowing and insider knowledge generation' (Eikeland, 2015, p384) thus creates praxis. Greenwood (2015) argues that practitioners lacking 'agency for praxis' cannot be said to be 'collaborative stakeholders, but mere research subjects' (p208). Such agency might be considered to be the space, both philosophical and practical, to engage fully with the research.

- AR is designed to solve a problem. Denscombe (2010) writes that an AR strategy's purpose is to solve a particular problem and to produce guidelines for best practice. This can be either an immediate problem, or reflection on a process of progressive problem solving, 'led by individuals working with others in teams or as part of a "community of practice" to improve the way they address issues and solve problems' (p6). Whichever it is, ‘Action research begins with the practical problems of a group of people’ (Ozanne & Saatciouglu, 2008, p2), and an important goal is to provide workable solutions (ibid).

- AR is locally based (but that does not mean it is confined to the local). As Argyris & Schön (1991, p86) write, ‘Action research takes its cues – its questions, puzzles and problems – from the perceptions of practitioners within particular, local practice contexts’. The aim is to generate local knowledge to be fed back into that setting (Herr & Anderson, 2015). The utility of knowledge generated by AR, to address the immediate needs of people in specific settings, is one of its major strengths. However, action researchers are committed to taking this knowledge beyond the local context to try to ‘inform wider improvements in society’ (Ozane & Saatciouglu, 2008, p2), and to bring together qualities of ‘engagement, curiosity and question posing’ on significant practical issues (Reason & Bradbury, 2008, p1).

- AR can be used in many different contexts. For example, McCormack & Dewing, (2012) describe four different paradigms of AR,

Table 5: Paradigms of Action Research (adapted from McCormack & Dewing, 2012)

Technical	Associated with the work of Kurt Lewin, influenced by the empirical-analytic paradigm**.**
Practical	Associated with the Tavistock Institute in developing AR with business and government (Winter & Munn-Giddings, 2001, p37), with an emphasis on meaning making, taking action arising from the development of shared interpretations of social reality.
Emancipatory	Empowering people to take action and change oppressive or limiting social structures. Associated with the work of Paulo Freire (2010) and Orlando Fals Borda (2006)
Transformational	Where, in addition to knowledge creation, transformation of researchers and participation is ‘both means and end’ of the research.

A general distinction can also be made as to whether AR falls more within the 'Northern' or technical tradition, exemplified by Lewin or the 'Southern' or radical tradition associated with Freire and Fals-Borda (Minkler & Wallerstein, 2017).

- In AR, the researcher collaborates with the participants, to 'collapse the traditional roles of the researcher and researched' (Gergen & Thatchenkery, 2004, p239). Although collaboration may not be straightforward, (Hammond, 2013), it is a widely shared aspiration. Zhang et al (2015) argue that it is only when the researcher understands the situation of the practitioner that relevant research can be generated, and that validation of that research by practitioners ensures that results can be actioned.

- AR attempts to bridge the theory/practice divide and build on theory because 'solely improving practice is not significant unless the research can build, inform and test social theory' (Ozane & Saatciouglu, 2008, p2). It does this by valuing experiential knowledge and emphasising the practical reasons a person might have for developing their understanding of a problem (Winter & Munn-Giddings, 2001). Whitehead (2018) moves this on to what he calls 'living theory' – an opportunity for practitioners to gain insights from others and examine their own practice in light of growing understanding of the socio-cultural and socio-historical location of that practice.

- AR uses a cyclical or spiral process that integrates action and critical reflection (Dick, 2015), though as Kindon et al (2007) note, it is not always clear how this happens in practice. In relation to this study, the cyclical process involves 'learning about practice, making plans to change practice based on the learning, implementing these changes and evaluating the success of these changes' (Spalding, 2009). The cycle is discussed further below, in relation to Lewin's work.

4.6 Professionalising Action Research

My research is located within the context of AR in health and social care, and I made the decision to utilise the model of Professionalising Action Research set out by Hart and Bond (1995; 1996; Hart, 1996), a 'typology [that] has been developed specifically for practitioners in health and social care (Hart & Bond, 1996, p153)'

The reason for this was that my research concentrates on how professionals work together to promote the welfare of service users, rather than how they work with service users directly (McClure, 2014). The focus at the outset was 'practice development' rather than being 'user focussed' (McVicar et al, 2012). Hart & Bond (1995, p43) call this approach 'professionalising action research' whereby practitioners are attempting change 'on behalf' of service users, and where the change intervention is aimed towards resolution of problems in the interests of research-based practice and professionalisation. Stuart (2014) describes having a similar aim in her study of collaborative working in children's social services which 'sought to improve the professional lives of people trying to deliver integrated care' (p3), and ultimately, to improve the lives of their beneficiaries, but did not directly involve children using the service.

Like McCormack & Dewing, (2012) above, Carr & Kemmis (1986) describe the 'technical', 'practical' or 'emancipatory' interests of AR, derived from Habermas' (1972) theory of knowledge-constitutive interests. Developing this, Hart & Bond (1995) describe a continuum of AR (see Appendix 2) from Lewin's 'rational social management' approach, which, they believe, does not disturb the status quo around research, to critical or participative AR aimed at structural change. Professionalising AR sits second to the end of this spectrum (McClure, 2014). In their 1995 book, Hart and Bond give seven distinguishing criteria of action research, which are cross referenced with four broad types of action research; 'experimental', 'organisational', 'professionalising' and 'empowering' which they see as having emerged from experimental research, organisational consultancy, education and nursing, and community development respectively.

However, in an article the following year (Hart & Bond, 1996), they condensed the seven criteria to three, (frustratingly with no explanation), and it is these on which I shall focus, namely the educative base that distinguishes the type of AR, the problem focus in that type and the improvement and involvement which is sought (see Appendix 2).

4.7 Locating my study within this typology

Hart and Bond (1996) break down each criterion in relation to where it falls on the ‘action research type’ spectrum. Thus they see, to the far left of professionalising AR on the spectrum, the educative base of experimental AR as ‘re-education in order to bring about a measureable change in behaviour’(p153), which appears to align it more closely with behaviourism (which Hart & Bond acknowledge), and would be anathema to many AR researchers. However, this type of AR is seen in the work of, for example, Argyris (1991), in Action Science. Hart & Bond see the educative base of organisational AR (left of professionalising AR on the spectrum) as aiming to overcome resistance to change in the face of managerial initiatives, which begins to link in with Lewin’s theory of change, mentioned above. To the right of professionalising AR lies empowering AR. This aims to raise the consciousness of its participants (Freire, 2010). For professionalising AR, located between the organisational and emancipatory types of AR, the educative base takes the form of reflective practice in which the practitioner develops by grounding knowledge and action in everyday experience.

In relation to the problem focus, Hart & Bond (1996) state that a feature of professionalising AR is that it is the professionals involved who identify and define the nature of the problem, unlike, for example, organisational AR, where the problem is defined by ‘the most powerful managerial group' (p154). I will further explore how the process of problem definition took place in this research in Chapter 6.

Regarding their third criterion, improvement and involvement, Hart and Bond (1996) see professionalising AR as seeking to improve professional practice 'for the purposes of increasing professional control and status' (p155). They do not elucidate on this but I take it, in relation to this research, to mean control and status in relation to multi-agency working, with other professionals, rather than control and status in relation to service users. They do, however, note that service users may be involved in professionalising AR, and this was an area that I considered carefully, (see chapter 2 & 5 for further discussion), ultimately concluding that this was not the focus of the study. This could perhaps be viewed though as a weakness in both Hart & Bond's typology and in this research. Winter & Munn-Giddings (2001) address this by acknowledging the potential for reinforcing professional power over clients. However, they argue that this misses the significance of the 'values' under consideration by professional participants – both the rights of the clients and the responsibilities of the workers, reflection on which, as they argue, is the means by which practice is improved (ibid), by practitioners questioning their own decisions and being encouraged to explore the contradiction between their professional values and their current practice.

Reflective stop off

I felt that this AR typology offered me a space in which to, at least initially, locate the research, particularly given the overwhelming number of models available, as noted above, and the lack of models which had been applied to multi-agency situations. However, from the start, I felt that my study did not sit fully within either the organisational or the empowering type, though as will be demonstrated in chapter 8, I shifted this position somewhat during the course of the research).

Hart (1996) argues that problems arise when action researchers are not clear about the constraints and possibilities of a particular 'type', and that this problem may be compounded as, during the life of a project, it may shift from one type to another as it moves through the different phases of development. Hart & Bond (1996) discuss how a feature of professionalising AR, being located between ‘organisational’ and ‘empowering’ types’ is the researcher (and the research) may be at risk of being pulled in two different directions, prone to being usurped by the management agendas of organisational AR on one side, and by politicisation by a shift to the empowering type (ibid) on the other. Hart herself experienced this tension in her own research where there was conflict about the extent to which her role was that of management consultant or academic researcher (p157), a situation in which I found myself, and which I will discuss in relation to my own positionality in chapter 5. Hart & Bond (1996) also note that there may also be times when,

> The unequal power relations between professionals and users, mirrors that of the organisational type. The indication that this may be happening is when professionals locate the problem in the user group and conceptualise improvement in terms of overcoming resistance to change on the users' part (p154).

This was an issue that also arose for me as the research progressed, and will be discussed later.

Hart & Bond (1996) suggest that these kinds of issues around the positioning of professionalising AR are what makes their typology useful to the researcher. It can make explicit any implicit agendas, and thus make it easier to identify and anticipate the impact of these. Furthermore, they see its positioning between organisational AR and empowering AR as a strength, as both of the other models have limitations in relation to trying to improve services.

Reflective stop off

What Lewin calls ‘diagnosis, in the first phase, Hart and Bond, (1996, p52) call the ‘problem-sensing phase’. I prefer this term, as ‘diagnosis’ has rather pseudo-scientific connotations which seem out of place for AR.

4.8 Using Professionalising AR in a multi-agency study

As Winter & Munn-Giddings (2001) note, AR is especially appropriate to promote multi-agency working. It is an ongoing, iterative process, suited to complex and rapidly changing situations (Yorks & Nicolaides, 2007), as may be exemplified by local authorities and health organisations. Lifvergen et al (2015) argue that an AR approach 'is a fruitful resource when engaging in multi-stakeholder interventions in complex care systems such as integrated care' (p338) and that systems transformation is possible if multi-stakeholder involvement is emphasised (although their study took 10 years to do this). Watts & Jones (2000) arguing that there are many commonalities between multi-agency working and AR, and that,

> It would seem logical to suggest therefore, both that AR could be a vehicle to promote and enhance inter-professional practice, and that the procedures emerging from inter-professional practice can illuminate certain aspects of AR. (p377)

Williamson et al (2012) hold that AR is useful and relevant for all members of the multi-disciplinary health care team who have direct clinical interface with patients. However, Lifvergen et al (2015) also argue that systems change is much more complex and unpredictable than suggested, and that Williamson et al (2012) over-simplify the 'universally applicable recipe' (p338) for change.

Although AR has been and is widely used in educational research with teachers, it has had a slower uptake in fields such as nursing, (Sparrow & Robinson, 1994; Koshy et al, 2011; Williamson et al, 2012) and social work. However, Titchen & Binnie (1993) suggest that nursing is similar to teaching in that practitioners in both fields have sought increasingly professionalised roles with increased individual accountability. The concept of increasing professionalisation was an important unifying factor amongst the groups who participated in my study (see chapter 3 for further discussion). Another unifying factor was the fact that the 'plan-act-observe-reflect' cycle would be familiar to many practitioners as mirroring the way in which they use reflection in day-to-day practice with service users/patients (Hart, 1996; Winter & Munn-Giddings, 2001). AR, then, may offer a means of developing reflective practitioners and producing knowledge for practice as part of a ‘professionalising strategy’ (Hart, 1996, p454; Lifvergen et al, 2015).

4.9 How far can professionalising AR be said to be participatory?

According to Kemmis & McTaggart (2005) one of the characteristics of AR is that it is fundamentally participatory. It is ‘where participants go to work on themselves, examining the relationship between knowledge, identity, agency and practice’ (Herr & Anderson, 2015, p17), and where participation is both a means of obtaining good outcomes and a worthwhile end in itself (Dick, 2015). Certainly, participation can be a powerful thing. As Kemmis (2009) writes of a project, ‘using participatory action research enabled participants to actively change how they conceptualised themselves and their practice’ (p463). But what constitutes participatory action research? What does it look like from the outside? What degree of participation by participants does there have to be for research to be considered participatory?

Hammersley (2004) believes that there are many different views about whether AR is necessarily a participatory undertaking. In an overview article critiquing the 2015 SAGE Encyclopaedia of Action Research, Dick (2015) notes that many entries purporting to be about PAR give little acknowledgement that choices can be made about the extent of participation, that full participation may be difficult or costly, and that participation often ‘isn’t as all-or-none as those quotes may imply … [and] I am left with the impression that the commitment to participation may be primarily ideological’ (p436). He observes that many key texts about AR in an educational context make little mention of participation, and that only a few AR practitioners are honest about the extent of participation, or even that it may not be possible. Waterson (2000) also feels that most accounts of AR are ‘success stories’, with little depiction of issues ‘behind the scenes’. There are important concerns for professionalising (multi-agency) AR. Whilst participation across agencies can build commitment to planned actions and facilitate information sharing (Dick, 2015), the institutions which employ the participants must be flexible enough to permit their involvement (Cornwall, 2008), participants must have the time and energy to participate (D'Cruz and Gillingham, 2017), and it must be possible for action to be taken as promised within the organisation (ibid). Hart herself (1996) argues that in the managerialist context of the NHS, participatory action research endeavours may become distorted into a method for getting people to collaborate with managerial goals, and internalise the values of the corporate culture.

Participation cannot just 'happen'. Zhang et al (2015) and Greenwood (1994) note that participation can't be imposed or mandated in advance, it must be generated, though one can begin with 'participatory intent', and it may increase as research progresses. Cornwall & Jukes (1995) believe that much participation is simply 'contracting people in to projects which are entirely scientist-led, designed and managed'. Participants may be sceptical about whether it is worth investing time and energy in a project which may seem to have little direct benefit (Cornwall & Jukes, 1995). D'Cruz & Gillingham (2017), who are refreshingly honest about why they were not as participatory as they could have been, and Meyer (1993), believe that the requirements on an academic researcher to produce work at a scholarly level may conflict with the ideals of participatory research.

Biggs (1989, p3) distinguishes four levels of participation that are typical in research projects; contractual, consultative, collaborative and collegiate. Cornwall & Jewkes (1995) argue that in practice, researchers move from one mode to another during the research process and that in reality the collegiate level, where researchers and participants work together in process of co-production and mutual learning, is rarely achieved. In the following chapters I will consider these levels of participation in relation to this research.

4.10 Quality measures in action research

Reason & Torbert (2001) highlight the importance of addressing questions of validity in first-person research. It is argued that AR requires different indicators of quality than traditional concepts such as validity or reliability (Reason, 2003; Reason & Bradbury, 2008) which have tended to be preferred by positivists (Herr & Anderson, 2015), but there are many differing suggestions about what these indicators should be. Indeed, for post modernists such as Kvale (1995; 2002), the very concept of validity must be questioned, as it were, for its validity (Reason & Bradbury, 2008), that is, questioned as a social construct in itself.

Although Herr & Anderson (2015) retain the term 'validity' in their five validity criteria for action research (dialogic and process validity, outcome validity, catalytic validity, democratic validity and process validity) they note, without explanation, that these were developed more for insider AR, which this study is not (I discuss my positionality in chapter 5). In Reason & Bradbury's (2008) work on 'broadening the bandwidth of validity' (p204) they suggest that questions for validity and quality should include those of emergence and consequences, significance, ways of knowing and outcomes achieved.

There is also work from Heikkinen et al (2007; 2012) which offers five quality criteria for AR, those of historic continuity, reflexivity, dialectics, workability and evocativeness. Reason & Torbert, 2001) building on Lather's (1993) work, propose four validity criteria for first-person research; situated, rhizomatic, reflexive and ironic (p27).

Reason (2003) connects the repudiation of the vocabulary of positivism with pragmatism, and highlights the call of Rorty to 'create our own vocabulary to describe what we take as quality in our research' (p105). However, as Winter & Munn-Giddings argue (2001) it is crucial that AR projects must 'seem convincingly and professionally sound' (p255) for them to be taken seriously by the wider research community. I did not feel that any of the criteria mentioned above ‘fitted’ what I wanted to demonstrate, and were inclined to conflict with and sometimes obscure my purpose. I felt that I needed a simpler and perhaps clearer vocabulary for my own study.

I therefore turned to the work of Lincoln & Guba (1985; 2003), who as Kvale (1995, p21) describes it, ‘have reclaimed ordinary language terms to discuss the truth value of their findings’. Lincoln & Guba (1985) have proposed that ‘trustworthiness’ is a more appropriate measure than ‘validity' for naturalistic enquiry. The components of trustworthiness are described in Appendix 3, along with suggestions from Shenton (2004) about how these criteria might be met. I am therefore using the concept of trustworthiness as a quality measure for this study.

However, Lincoln & Guba (2003) also consider another measure, ‘authenticity’ (Appendix 4). Bryman (2016) notes that although the authenticity criteria which Lincoln & Guba set out are ‘thought-provoking, [they] have not been influential’ (p386). I felt that their criteria for authenticity were not only extremely relevant for an AR project, as Bryman (2016) concedes, but fitted a social constructionist paradigm in perhaps a better way than some of the criteria specifically suggested for AR. Above all, demonstrating authenticity means asking,

> Are these findings sufficiently authentic that I may trust myself in acting on their implications? More to the point, would I feel sufficiently secure about these findings to construct social policy or legislation based on them? (Lincoln & Guba, 2003, p274).

The question as to whether one can reasonably act on the implications of findings is a highly pertinent one, and little acknowledged by other validity frameworks. As will be demonstrated in later chapters, although I was not seeking to construct social policy or legislation, these considerations assisted the development of locally based practice guidelines. They also helped me to see how current social policy and legislation was congruent with, or divergent from, my findings. Thus, both the concepts of trustworthiness and authenticity have been employed in this study.

4.11 How social constructionism and pragmatism inform action research

Gergen & Gergen (2015) describe a significant relationship between the development of AR and social constructionism. They note that the collectivist orientation of AR is in 'full harmony with the constructionist account of knowledge formation' (p405). They also believe that the 'catalytic value' of constructionist ideas allow researchers to stand outside the realities created by the research and reflect on how they could be altered or enriched (ibid). Gergen & Thatchenkery (2004) contend that a postmodern critique favours a constructionist view of research.

Greenwood believes that the scope for action in AR is contingent upon the premise that 'the social is constructed and therefore can be reconstructed' (Greenwood, 2015, p201). If we accept the premise that truths are socially constructed rather than simply uncovered, then AR is an opportunity to 'co-construct and embed a desired reality built on participants' experiences and aspirations' (Bellinger & Elliott, 2011, p711). As Stringer (2014) notes, AR does not seek to present definitive answers to problems, but to uncover the different constructions held by participants, in an attempt to move forward.

4.12 What is social constructionism and where did it come from?

Social constructionism, viewed as relativist ontology, describes a tradition of scholarship that 'traces the origin of knowledge, meaning, or understanding to human relationships' (Gergen & Gergen, 2015, p402). Both Schwandt et al (2000) and Susman & Evered, (1978) see parallels between social constructionists and interpretivists in their assumptions about the social world and how it is created. Crotty (1998, p61) notes that the phenomenological movement of Husserl and Heidegger was 'thoroughly imbued with – indeed predicated upon – the spirit of social constructionism'. Thus it is not a positivist, empirical perspective. It is instead a direct response to both objectivist theories of social problems and to positivist mainstream research on social problems (Schirmer & Michailakis, 2016 & Schirmer, 2014). Gergen & Gergen (2015) argue that the terms 'social constructionism' and 'constructivism' are often, (and wrongly), used interchangeably in the literature, though the former ascribes the creation of knowledge and meaning to human relationships, as opposed to a process of the formation of individual experience described by the latter.

The work of Mannheim (1893-1947) on the sociology of knowledge, and Berger & Luckmann with their seminal text 'The Social Construction of Reality' in 1967, is seen by Crotty (1998) to have begun and developed the scholarship around social constructionism, though Berger and Luckman themselves (1967), trace it back to Marx's root proposition, 'that man's consciousness is determined by his social being' (p17). Burr (1995) adds the work of sociologist Mead (1934/2015) who founded symbolic interactionism, fundamental to which is the view that it is through everyday encounters with others that we construct our own and others' identities. However, Burr argues that social constructionism has a more multi-disciplinary background and notes the importance of the perspective derived from social psychology, particularly the work of Gergen, from the 1970s onwards. Gergen himself sees social constructionism as a 'means of broadening and democratising the conversation about human practices' and continually reflecting on these (Schwandt, 2000, p200). The parallels with AR are clear, and suggestive.

Gergen & Gergen (2015) consider that Berger & Luckmann's work lacks a political critique. Instead they describe how the convergence of three movements; critical, literary/rhetorical, and social, provide the basis for contemporary social constructionist thought. The critical movement they define as 'the mounting ideological critique of all authoritative accounts of the world' (p402), going back to the Frankfurt School (Greenwood, 2015), and embodied more recently in the work of Foucault and other poststructuralist and postmodernist theorists. The literary/rhetorical movement, they argue, highlights how explanations and descriptions of the world are ‘not so much dependent on the world in itself as in discursive conventions’ (ibid). The social movement Gergen & Gergen (2015) see as being the focus on social processes as giving rise to knowledge. Greenwood (2015) suggests that the very act of creating spaces for reflection by the diverse stakeholders in an AR project promotes social change by deconstructing and constructing new meanings and models. But Gergen & Gergen (2015) see that this affinity may also involve tensions, and they acknowledge criticisms of AR, one being that it is not cumulative, but rather composed of ‘insular initiatives that seldom speak to each other’ (p406) unlike the advances in knowledge that are possible within a positivist paradigm.

4.13 Social constructionism and pragmatism

Gergen & Gergen (2015) see social constructionism as being closely allied with a philosophically pragmatic conception of knowledge, and Crotty (1998) describes the development of pragmatism in America as a parallel development with social constructionism. Pragmatism ‘rejects positivism whilst also rejecting out-and-out subjectivity’ (Hammond, 2013, p608) and posits that ideas and practices should be judged in terms of their ‘usefulness, workability and practicality … a perspective that stresses the priority of action over principles’ (Reason, 2003, p104). It derives from the work of American philosophers, such as Peirce, James and Dewey in the early 1900’s, and latterly, writers such as Rorty. Dewey believed that ‘we construct our own sense of reality *and* our sense of reality is formed by our experience of the environment’ (Hammond, 2013, p606)**.** Particularly from Dewey and Rorty, Greenwood (2015) believes, comes the idea that research must engage in practical action, because,

> Without pragmatic action, in a system of collaboration among all the stakeholders, there is not only no change, but also no meaningful and sustainable theoretical learning. (Greenwood, 2015, p200)

Hammond (2013, p605) considers whether pragmatism can provide the epistemological underpinning for AR, particularly in relation to the work of Dewey. In an interview with Rorty, Reason explores the links between the pragmatism and AR, but finds that although Rorty agrees there is a link:

> What I was dubious about . . . was, do (people) really need a new kind of language or do they just need less talk about what it is they are doing or what our method is? It's as if you are giving them a new meta-discourse instead of just saying skip the meta-discourse and just get on with it. (Reason, 2003, p109)

There is by no means consensus in the literature about the influence of either pragmatism or social constructionism on AR, and for some, such as Hammersley (2004), AR includes more in its epistemological positioning, drawing also on positivism, interpretivism, critical theory and postmodernism. Susman & Everard (1978) emphasise the links between AR and existentialism, phenomenology and hermeneutics.

Whilst Reason (2003, p119) suggests action researchers should 'celebrate and live out our epistemological heterogeneity', Hammond (2013) argues that whilst this theoretical eclecticism can be seen as a virtue, it can also mean that important difference are obscured, and the focus of AR becomes too fixed on problem solving. But for Hammond, the point is that 'action researchers carry pragmatic assumptions about knowledge when conducting their work' (ibid, p609) though these may not be made explicit.

4.15 Conclusion

In this chapter I have outlined my reasons for choosing to locate this research within an AR framework. I have considered the foundations and key characteristics of AR, and discussed my reasons for choosing to locate the study within a professionalising action research typology, the extent to which it can be participatory, and the quality measures that were used in the study. I have considered the location of AR within social constructionism and pragmatism. In the next chapter, I will discuss the first step in the AR process, planning and problem sensing.

Chapter 5 – Professionalising Action Research: Planning the study

5.1 Introduction

The purpose of this chapter is to set the scene for the research, and explore further the conceptual framework for the study. In previous chapters I discussed the existing theory and research in respect of self-neglect and multi-agency working, and the rationale for using an action research methodology. In this chapter I will critically reflect on how I set about the 'diagnostic' phase of the study (Lewin, 1946), in relation to developing my understanding of the problem to be explored, setting up the study and completing the first phase of data collection ('fact finding'). AR involves 'an initial analysis including critical reflection, fact finding and conceptualisation about the problem. This is followed by planning and delivery of an intervention, which in turn is followed by more fact finding or evaluation' (Sandars & Waterman, 2005, p295) and the start of this process will be described here.

I will consider the importance of reflexivity and will investigate my positionality in relation to this research, based on knowledge gained from my own experience. In so doing, I will discuss the interviews and workshops which were methods used in the study, to illustrate my points. I will discuss the findings from these more fully in relation to their contribution to the overall research in the next chapters. I explore issues such as recruitment to the study, and gaining ethical approval for an action research study. In line with Lewin's first phase of AR, I then describe the exploratory phase of my research. I will discuss the methods used, with particular focus on the challenges of the group interviews and the development of my own critical subjectivity. Finally, I will outline data recording and transcription considerations.

5.2 Reflexivity

> Reflexivity uncovers the social at the heart of the individual, the impersonal beneath the

> intimate, the universal buried within the most particular (Bourdieu, 1992, p44)

Reflexivity, or ‘knowing-in-action’ (Schön, 1987), is an ongoing process, throughout a research process, as the researcher responds to events as they unfold with a critical awareness. Reflexivity also acknowledges the inseparability of theory and practice, values and action (Banks & Gallagher, 2009). Bryman (2016) argues that researchers should be both reflective about the methods they are using, and the values and biases they bring, and also demonstrate a reflexive awareness about the social, political and cultural context within which they operate. D’Cruz et al (2007) ascribe three variations of meaning to reflexivity. The first concerns the individual’s ‘considered response to an immediate context and making choices for further direction’ (p75). In chapter 7, I describe how I experienced this during the first workshops that I ran, when I very quickly had to make a key decision in light of the response from participants, which would have implications for how the research progressed. D’Cruz et al (2007) describe the second meaning as being associated with a questioning, critical approach to practice, which inevitably includes self-scrutiny. I will explore this here in relation to my positionality in this research, for example the tacit knowledge and assumptions that I brought with me into the research (and which I sometimes found very difficult to disguise) and the moving between different roles in the research. In my discussion of running group interviews, later in this chapter, I was very aware of myself, as a middle aged white woman, in the difficult situations I found myself in, and this led me to the third type of reflexivity described by D’Cruz et al (2007), that of considering why we have a particular emotional response to a situation. Thinking through why I felt uncomfortable and upset helped me to see what was difficult in the situation for me and enabled me to become more confident at conducting the interviews. For the action researcher, being reflexive means being able to go beyond initial judgements and see them as the start of a learning process (Winter & Munn-Giddings, 2001), and I have found that I have had to repeatedly challenge my judgements, and interrogate why I was, for example, choosing one particular method of data analysis over another. Berger (2015) argues that reflexivity thus challenges the idea that knowledge is objective or that it can be produced independently of the researcher, important concepts for AR. However, Finlay (2002) describes reflexivity as ‘perilous’ (p212), and D’Cruz et al (2007) argue that the concept of reflexivity must be treated with caution as, for one thing, it may simply be a way of heading off criticism of one’s work. They argue that a research journal or diary, such as I kept, can be simply a way for a researcher to construct a version of their research which legitimises their knowledge claims. As a researcher, it can be difficult to know which way to turn.

5.3 Positionality

In any social encounter, people position themselves, or are positioned in certain ways, and one of these may be as insiders or outsiders (McNiff, 2017). Titchen & Binnie (1993) compare insider and outsider action research. They suggest that insider research is more successful, although Sparrow & Robinson (1990, p352) argue that this is not the case. Deutsch (1981) describes the ‘Catch 22’ in research whereby one must be enough of an outsider to be (relatively) objective, but enough of an insider to define and understand the issues being studied, and I felt this was highly pertinent for me. Maxwell (2013) suggests that one of the sources available to a researcher in constructing the conceptual framework for a study is one’s experiential knowledge, and therefore I thought very hard about my own positionality in this research. Deutsch (1981) writes that ‘we are all multiple insiders and outsiders’ and that one’s positionality as a researcher is ‘a process of ongoing evaluation (p123). I felt that I needed to consider three different aspects of what I brought with me as a researcher to this research.

First was my identity as a social worker. As I carried out interviews with staff from different agencies for this research, I started to realise that, as research into multi-agency working repeatedly shows, I actually knew very little about what the other groups in the study did. I was clearly an outsider with these groups, though I was able to understand the specialised vocabulary, institutional talk and indexical expressions (Morriss, 2016) shared by all of the professionals involved in the study. Increasingly, as I carried out the group interviews with practitioners other than social workers, I went through a process of reflecting on the way I had conceptualised all of these other groups when I was a practitioner and, essentially, how inaccurate that conceptualisation was. I felt that I was experiencing what Herr & Anderson (2015) describe, whereby in moving along the 'continuum of positionality' (p60) there is a shift in the relationship of the researcher to the setting. I began to see 'the taken-for-granted aspects of [my] practice from an outsider perspective' (ibid). On reflection, I was initially highly sympathetic to the social workers, but over the course of the group interviews, this changed significantly. Herr & Anderson acknowledge this dual insider/outsider positionality for academic researchers who have been practitioners, and note that many researchers have been practitioners.

The second aspect of my identity which I needed to consider was that I am a lecturer, and have continued to teach during the research, which has had implications for me. It meant that I knew some participants as ex-students, who had found jobs in the local authorities involved, although I often did not realise this until they identified themselves after the group interviews. Nevertheless, it meant that they knew me as 'lecturer Elaine' rather than 'researcher Elaine', though it is impossible to know what impact this may have had on their responses. This split identity manifested itself in a very direct way when I ran a group interview at which a current student was present, because she was on a placement in the team I was interviewing. I found that very challenging, because, as the student was doing a dissertation herself (and I had taught her on her research methods module), I felt pressure to try to model excellent practice in how I ran a group interview, got consent, asked and answered questions and so on. As I noted in my journal, 'that was really putting my money where my mouth was'.

Thirdly, as part of my job role, I deliver training to local authorities, particularly around adult social care law. This presented me with challenges. Participants were aware from the consent forms and participant information sheets that I came from a university, and which university I came from. It meant that, on occasion, I found myself in the situation where I was seen as an ‘expert outsider’ by participants in the group interviews, although I endeavoured to conceal my perceived ‘expertise’,

Journal entry
There have been several examples, in group interview discussions about the legal framework, of people getting the law wrong, around mental capacity particularly. In some cases participants will turn a question back to me, and ask me what is the right thing. It is really hard to provide a non-committal response to, even though I usually know the actual answer.

An action researcher walks a precarious line between academic researcher, consultant and trainer (Hart & Bond, 1995; Storey & Prashad, 2017). The contradictions of having in-depth insider knowledge and expert outsider knowledge was at times very difficult to manage,

Journal entry
Sometimes it can be very hard to hide the experience and knowledge that I have. I wanted to say yesterday [at a meeting of the Safeguarding Adults Board] ‘look, I’m an outsider now, but I was an insider for a long time, so I know what this game is all about and what is possible, and how it is so easy for processes to swing into action and not listen to what practitioners are saying’. But I didn’t.

Maxwell (2013) observes that, traditionally, what is brought to research from one’s own background has been treated as bias, to be eliminated from the research design, rather than a valuable component of it. Overall, reflecting on my positionality in this way has helped me to see where my areas of bias may be, and to try to minimise, or at least acknowledge these where appropriate and where possible. For an action researcher though, as Greenwood (2015, p204) believes, ‘central to AR is the rejection of the epistemology that equates knowledge with unmediated objectivity with the researcher as a spectator rather than an agent in the reality being dealt with’. However, that does not mean that the researcher should not continually be questioning their objectivity, certainly in the data-gathering phase.

For me, I felt this manifested in two ways. The first was the decision to be as anonymous as possible, rather than use my professional identity as a ‘calling card’. When I began doing my group interviews for the first stage of the research, I initially identified myself to the participants as a social worker ‘by background’. After the first one or two group interviews that I carried out, I reflected that it seemed to change how people felt towards me to have this knowledge, and that it potentially hindered people from speaking honestly. One participant actually said that he did not want to offend me by talking frankly about his views of social workers. However, as time went by and I became more confident in myself as a researcher, and learned more about other professional groups, as described above, I quite naturally referred to my own insider status less and less.

The other decision that I made in the early data-gathering phase was to try to minimise professional camaraderie, which could be a conflict in AR. Lyons & Coyle (2016) write about the tendency for ‘faking friendships’ (p39) in qualitative fieldwork through the deliberate use of certain interpersonal skills for building rapport. A social worker relies on their interpersonal skills to build a relationship and encourage rapport with service users, so this is an easy trap for me to fall into, as I noted in my journal,

Journal entry
So it was obviously different for me when I was interviewing social workers than when I was interviewing the police, though I could still use a sense of camaraderie, eye rolling, ‘we’re all in this together at the end of the day’. ‘We’ve had cuts but you’ve had cuts too, so you know what it’s like’.

I think this position appropriately shifted in the action phases of the research, when the participants and I were by design ‘all in it together’, as I will discuss in subsequent chapters.

5.4 Critical subjectivity

Critical subjectivity is a concept that relates to, and extends, positionality. Heron & Reason (2009) argue that 'we don't have to throw away our personal, living knowledge in the search for objectivity, but are able to build on it and develop it' (p149). They term this 'critical subjectivity', which Reason (1994) further defines as meaning that,

> Critical subjectivity involves a self-reflexive attention to the ground on which one is standing (p327).

Maxwell (2013, p46) suggests that a way of exploring one's own assumptions, biases and experiential knowledge can be through writing a 'researcher identity memo', both before beginning a study and at any point during it. This memo may include the expectations and beliefs that the researcher brings into their research. Before beginning my study, I wrote the memo below (Figure 2) which enabled me to see more clearly where the risks were for me in terms of my suppositions and beliefs, and where my strengths might lie in undertaking this research.

What do I believe about self-neglect and multi-agency working?

- That self-neglecting service users should be helped to remain in their own homes where this is practical and possible.
- That there does often come a point where people cannot, just out of common humanity, be left to live in squalor, and intervention has to occur.
- That self-neglect is not really a safeguarding issue, despite inclusion in the Care Act.
- That the binary decision making framework provided by the MCA 2005, is very difficult for practitioners to operate in day-to-day decision-making.
- That many social workers are unable to define their role to themselves and others.
- That many of the other professionals that social workers work with can be deliberately obstreperous, and very 'precious' about their own role.
- That working for the NHS is much more pleasant than working for a local authority.
- That although I had experienced high levels of disagreement between different professional groups in my life as a social worker, because of the time that had elapsed since I was in practice, and the developments in collaborative working, things had probably improved.

Figure 3: My beliefs in relation to the research topic

5.5 First, second and third person action research

In chapter one, I discussed the several ‘I’s’ described by McNiff (2017) as being central to an AR dissertation; the scholarly ‘I’, the critically reflective ‘I’, the dialectically critical ‘I’ and the meta-reflexive ‘I’. When I began this study, I struggled with the idea of where I was located, as an action researcher. Did I write about myself and the process that I was going through? Or did I just write about the actual project? How could I avoid the ‘self-indulgence’ (D’Cruz et al, 2007, p79) of placing myself at the centre of any account of the research? I have found the work of Wicks & Reason (2009) helpful in this respect. They believe that there are three broad pathways for AR practice,

> First person in personal reflective practice, second-person in relation to face-to-face community, and third person where the community of practice is too wide for face to face communication and one is seeking to contribute to the development of a social movement (p247).

I feel that during the course of the research I have moved back and forth between a first person position, building my own ‘internal meditative and reflective space’ (ibid) and a second-person position, developing the working partnership with my participants, and that one naturally informs the other. Logically, the first-person predominated during the initial exploratory phase of the work, as I thought my way through the research question and began to focus on opening and developing a ‘communicative space’ (ibid) with others.

5.6 Action Researcher as Bricoleur

With these contradictions around my own positionality and my researcher role, I found it helpful to consider the concept of action researcher as bricoleur (Greenwood, 2015; Gergen & Gergen, 2015; Maxwell, 2013). Greenwood (2015) describes the bricoleur as,

> A pragmatist whose central goal is supporting the stakeholders in addressing their problems... the bricoleur is an experienced craftsman (sic) who is not simply throwing ideas and methods at a problem but whose experience and capacity for reflection helps guide the processes in positive directions (p201).

I found it reassuring to reflect that my experiences and who I was could be used positively, rather than as something that merely muddied the water.

One has to perhaps beware of the empirical eclecticism espoused by some authors in relation to the bricoleur role (e.g. Maxwell, 2013; Dick, 2015), which may feed into criticisms of the weaknesses of AR explored in chapter 4. However, the concept of bricolage in AR can be seen as a way of maximising stakeholder involvement (Greenwood, 2015) and allowing the researcher to engage in 'creatively employing the available tools and materials to come up with unique solutions to a problem' (Maxwell, 2013, p42).

5.7 Planning the study

The study took place in two local authorities in the North of England, described here as Authority 1 and Authority 2. To avoid the conflicts that I had previously experienced as described above, I did not want to carry out the study in a local authority in which I had worked, so these were both authorities that were relatively new to me. However, I had provided training in both authorities previously, so had some contacts in both. Initially a great deal of thought was given to whether working with one authority would suffice, but I felt that because of the risk that I might not be able to recruit participants, it was better at the outset to include two authorities.

5.7.1 The problem-sensing phase – pilot work

> Unlike traditional research, it is often hard to distinguish a pilot study from the real thing. In AR, a pilot study is likely to simply be early cycles of research in an ongoing research spiral (Herr & Anderson, 2015, p86).

AR is premised on the idea of a problem which needs addressing – the first stage of AR, in Lewinian terms, is problem diagnosis; for Hart and Bond (1995), AR is distinguished by the fact that it is 'problem sensing and problem-focused' (p52). This is a difficult line for the action researcher to tread, as it may be seen that one is introducing a bias in suggesting that there is a problem in the first place (Cunningham, 1993). However, as Kennedy (2001, p68) notes, 'the word 'problem' implies that there is something wrong, whereas in action research a 'problem' is merely a recognition of the need for a specific change'.

Fenge (2010), notes that a preliminary pilot study can be a useful way of exploring issues in relation to participatory methodology. In 2012, I wrote a research review for the Community Care website, reviewing the latest research into self-neglect. Following the online publication of this, I was contacted by a local authority in the North East of England, to ask if I would be interested in running an event with a group of social workers to explore how to best support service users who self-neglected. I was told that this was an area that social workers had identified as one where they were struggling with practical solutions. This was three years before the Care Act 2014 came into effect (in April 2015), so self-neglect was not included in safeguarding at this time.

In the event, it was not only social workers who attended the two workshops which I facilitated, and the groups included occupational therapists and Carer Services managers. It became clear that the problems facing the participants were not just in working with service users who were self-neglecting, but also in working with other agencies in relation to people who self-neglected. We were discussing the case study 'Alice' (RiPFA, 2015), of a typical self-neglecter. I asked the participants to draw a 'professional' eco map (Parker, 2017) showing who were the people surrounding Alice (examples given below), indicating,

- Who they saw as closest to Alice and who furthest away
- What they saw as the philosophy of each group or person in relation to self-neglect
- What they saw as the level of tolerance of each group to self-neglect
- How they saw the quality of relationships between the different groups

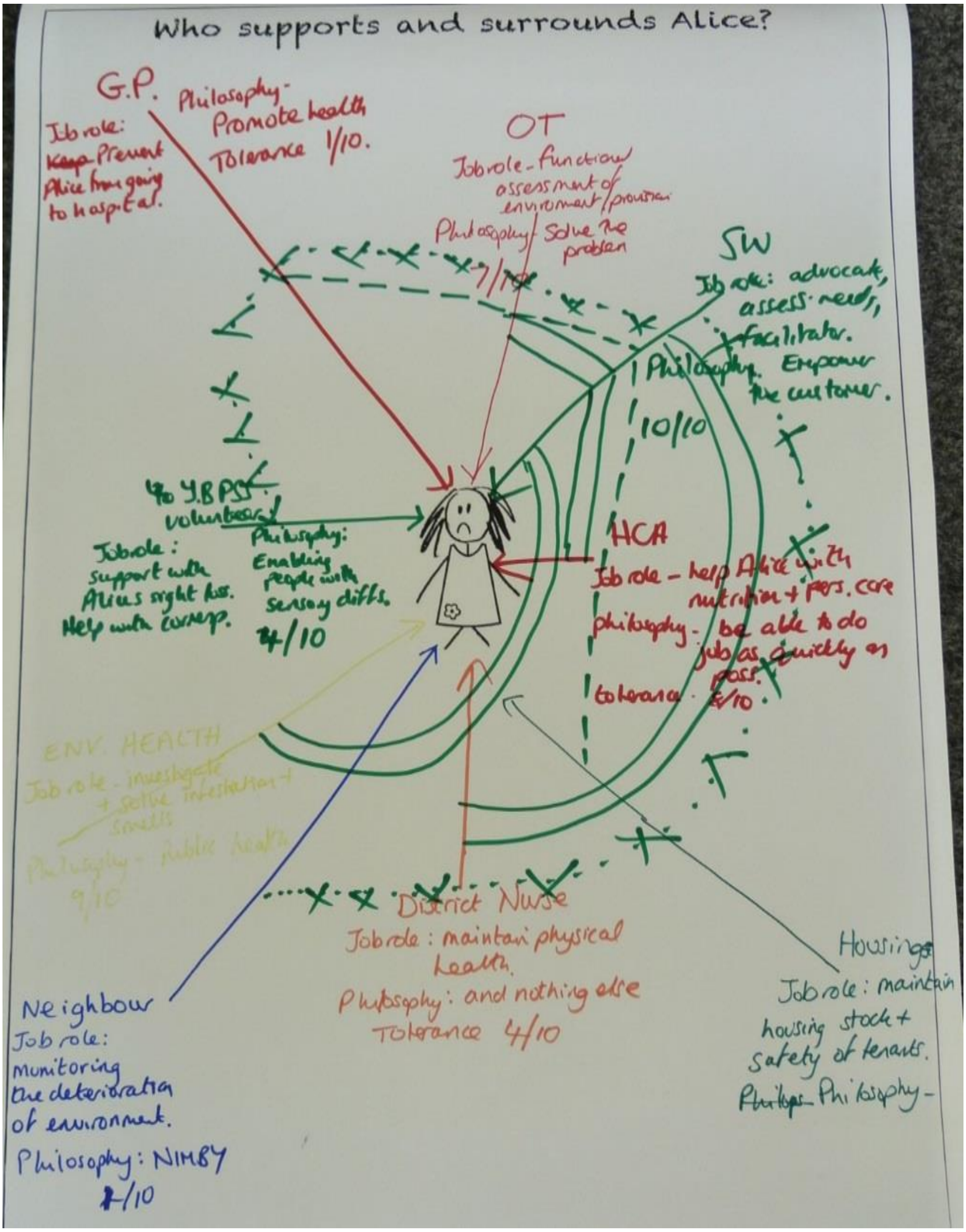


Figure 4: Eco map, Alice, Example 1

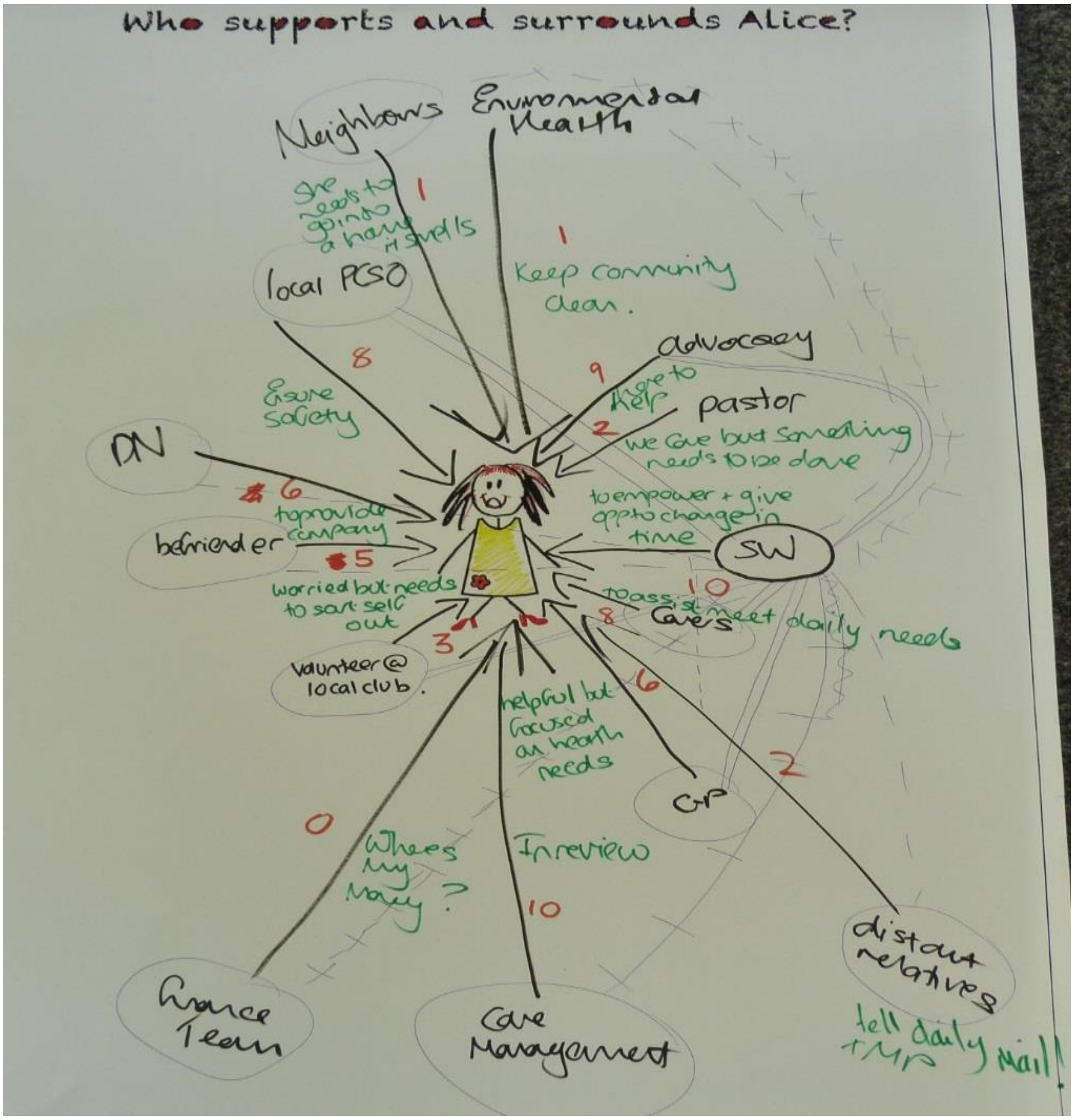


Figure 5: Eco map, Alice, Example 2

At this point, I had not asked participants to distinguish between non-professional support, such as neighbours or relatives, and professional support. Although these eco maps were messy and over-complicated (a learning point for me to keep my instructions simple), they identified very clearly who were the distal and proximal practitioners (those near the centre, those further away), and the 'key players'. They also identified those practitioners who were physically proximal (literally 'hands on', such as paramedics and home care workers) or environmentally proximal ('in the house', such as social workers, RSPCA, police). This helped me to develop my understanding of the views of the practitioners, an important use of pilot studies (Maxwell, 2013). The participants had begun to define the problem.

I mentioned above the use of a pre-prepared case study in the workshop. All participants had been asked to come prepared with a case study from their own practice which they wanted to discuss on the day. Stuart (2012) notes that her pilot research indicated the importance of using real cases to avoid the relating of espoused practice to hypothetical cases, and I was keen to do this. However, in the event, none of the participants brought a case study with them. Reasons given were that they had not had time, or that they had forgotten. This did not however mean that live cases were not discussed at the workshop; they very much were, as they also were in the main study (see below and subsequent chapters).

Participant feedback from the day showed how much value participants placed on just being able to talk to each other about issues relating to self-neglect and multi-agency working:

Participant feedback: What was useful about the day?

- Hearing professional views outside the workplace
- Hearing other cases and what they did to help broadened my own
- knowledge
- It was useful to discuss ideas around self-neglect and get other views
- Being able to discuss self-neglect with people working in other areas/other professionals/differing lengths of experience
- Case discussion, hearing about what other people have done
- Skill sharing with experienced colleagues from different service areas
- The information shared between people
- Useful to have the time to explore self-neglect issues, and discuss case studies.
- The free flow of conversation in a room of like-minded professionals
- Discussion around mental capacity and risk is very useful

Figure 6: Participant feedback: What was useful about the day?

I felt the content of this feedback boded well for an AR project, whereby, as Green & Thorogood (2014) argue, simply being in a group can bring changes. Taking the ideas from this exploratory research, combined with my own experiential knowledge and existing theory and research (Maxwell, 2013), I began to develop my PhD proposal.

5.7.2 Developing the research questions

Cunningham (1993, p75) argues that in AR terms, ‘a problem is a definition of a need for change and describes how certain issues can be addressed’. Sandars & Waterman (2005, p300) suggest that AR therefore requires ‘a special kind of research question’, with intervention framed as deliberate, as in ‘How can … be improved to improve professional practice?’. I needed a question that would also serve as a title for promotion of the study to participants, something that was direct and accessible. Thus, the working title and central question of the research became ‘How can professionals improve the way they work together to promote the welfare of service users who self-neglect?’

Following this, I developed an interview guide, which would ‘serve as a road map plotting the course of the interview from start to finish’ (Doody, Slevin & Taggart, 2013b, p170). I used a semi-structured approach, with a number of open-ended questions to stimulate discussion and to enable me to probe any unplanned responses (Appendix 5). I considered the number of questions that I should ask. Gray (2014) suggests around twelve, with less for a more complex issue, or for a more heterogeneous group. There should be a balance between general and more specific questions (ibid), and Gray (2014, p477) suggests a ‘funnel’ approach , where the introductory questions allow the moderator to gain insight into the basic opinions of the group, before moving on to the more specific questions. However, as Gray (ibid) notes, group discussion may lead in unexpected directions and away from the question schedule, hence it may be more useful to think of it as an interview guide (Doody, Slevin & Taggart, 2013b).

5.7.3 Ethical approval issues in a multi-agency study

I had decided to use group and individual interviews for the problem-sensing phase of the research (see 5.8 below), and intended to undertake interviews with representatives from all of the groups who might be involved in a self-neglect case. Both the university and some of the agencies with whom I proposed working have stringent processes for obtaining ethical approval before any research can begin. The dynamic and participatory nature of AR means that it can be difficult to be prescriptive about what the action phase may involve (Stringer, 2014; Hart & Bond, 1995), which can make gaining ethical approval difficult (Brydon-Miller & Greenwood, 2006). Therefore, rather than gaining ethical approval for the whole study at the outset, I submitted staged applications to the university research ethics committee (REC), as the research developed, as recommended by Brydon-Miller & Greenwood (2006).

Table 6: Ethical approval

Date of submission	Approval type and purpose
November 2015	Full ethical approval for group interviews and individual interviews
February 2016	Major amendment for inclusion of further professional groups into the study
February 2017	Full ethical approval for multi-agency participatory workshops and virtual action learning sets
May 2017	Minor amendment for approval to contact participants post-workshops

After gaining approval from the university REC in November 2015, I had to seek approval from all of the agencies who I was hoping would be involved in the study. There proved to be absolutely no consistency in the preparedness of different agencies to participate in research. Some agencies had robust and demanding ethical approval processes, others minimal or non-existent processes. For the latter group, I was generally able to proceed by obtaining gatekeeper consent.

The process of obtaining approval from bodies employing NHS staff was extremely complex.

At the time I did not need full IRAS (Integrated Research Application System) approval, as the study did not involve patients. However, I had to obtain an NHS research passport in order to be able to access staff and the NHS premises where I hoped to carry out my interviews.

Journal entry
I have been asked to provide for my research passport, my National Insurance number, my home address, my date of birth, and my CV, but am at a loss to see why any of these things are relevant. Additionally, my employers have been asked to confirm that they have seen two references, photo ID, done a DBS check, investigated gaps in my employment and so on. If I want to access NHS premises, I have to provide all of this information. It seems to me that no one is asking the question of whether it is ethical to be asking a researcher to provide all of this confidential information. I am not told who will read the information or have access to it, nor for how long it will be kept.

I then had to seek approval from the Community Trusts, Mental Health Trusts and Clinical Commissioning Groups in both areas. In some cases, this involved more than one CCG or Community Trust, as their boundaries were not coterminous with the local authority. I had to seek separate ethical approval from the ambulance service, the fire service and the police. All of these organisations had their own processes and requirements and gaining ethical approval to speak to all of these staff was extremely time-consuming. One Trust in particular also required regular progress reports, including numbers of participants, throughout the study.

I identified in the literature review that there were very few studies which adopted a truly multi-agency perspective. Having experienced the complexity of the ethical approval process in relation to both an action research study and one involving many organisations, I would concur with Brydon-Miller & Greenwood (2006) that researchers may be dissuaded from looking at important issues ‘simply knowing the hurdles that they will face in attempting to gain [ethical] approval’ (p122). Brydon-Miller & Greenwood (2006) also suggest that developing a research proposal and a consent form for an AR project should be a collaborative process between researcher and participants. Because of the paramountcy of getting over the ethical hurdles before encountering a participant, it is difficult to see how that could happen in practice.

Feedback from my initial ethics application was that I had not made it clear on the participant information sheet whether participants in group interviews could withdraw from the study (Sandars & Waterman, 2005). I therefore revised my consent form and participant information sheet to clarify that participants could withdraw at any time before or during the group interview without giving a reason, but if they withdrew during or after the group interview their data would still be used for the study. This is because it would be highly problematic to remove their voice from a recording and their words from a transcript. In the event, no participants at any stage of the research withdrew.

5.7.4 Piloting the questions

I then carried out a pilot group interview with volunteer colleagues, who all worked in some of the professions that would be represented in the study, though none of them were social workers. This in itself was a fascinating process, and confirmed some decisions I had made. Firstly, it indicated if I had made basic mistakes in my phraseology. For example, in one question, I had asked about 'capacity' rather than 'mental capacity' and participants misunderstood that to mean 'workload capacity'. On looking at the transcript, I was able to identify which questions were most meaningful to participants and provoked good discussions, which were less successful, and if any were potentially biased towards my own background and views as a social worker. These could be re-phrased, or omitted. Most importantly, the pilot group confirmed me in my decision to hold uni-professional groups in the preliminary phase (see below for further discussion of group composition). Even though the participants were colleagues, they had very different professional backgrounds, and it was interesting to observe the levels of (polite) conflict between them. I also carried out an individual interview with a friend who works in Housing, and again this enabled me to test the relevance and usefulness of the questions.

5.7.5 Negotiating entry into the client system (Dick, 1993)

AR depends on the 'careful initial building of relationships and negotiation of roles, often referred to as the entry process' (Herr & Anderson, 2013, p114). It was clear that the range of agencies which I wanted to include in the study meant that it could be potentially be very time consuming to negotiate each individual client system. However, there was a structure that I could utilise to do this, which was the Local Safeguarding Adults Board (LSAB) in each local authority area.

The Care Act 2014 made it mandatory for each local authority to set up an LSAB, which is an important statutory body for co-ordinating and fostering partnership working. The LSAB was the mechanism by which access was obtained for the research, and support provided for the action phase of the research. My hope was that the LSAB's would be the 'sponsors' of the research (Gray, 2014,) who would give 'political' backing and be 'willing to speak up for the project when asked' (p330). I certainly could not have done the research without their approval.   It was important that representatives on the board were of sufficient seniority to be able to operationalise any changes arising from the research and identified by practitioners (Hart & Bond, 1995), as was described to me later in the research,

> All the players are on the board, aren't they, at a senior level and hopefully they can drive through some of the actions and changes as well that are out of the control of frontline staff (Participant at workshop).

I started in each local authority by negotiating attendance at the LSAB's, which are led by an independent chair and are attended by representatives from nearly all of the partner agencies I wanted to involve in the study. However, representation did vary between local authorities, and a study of LSAB's (Braye et al, 2012) found that board membership varies widely, with anything from 10-47 members, which makes for a very complex picture.

At each LSAB meeting I obtained a slot on the agenda, gave a brief power point presentation about the aims of the research, answered questions, and asked for the support of the Board. Both of the Boards gave permission for the study to take place. In both cases, it was the independent chairs of the Boards who were most keen to take part. On reflection, I realised that this was easy for them, as it had no further implications for them in terms of workload. As I reflected in my journal,

Journal entry
I have discovered that the link between these Boards and their operational staff is very weak. The Board saying yes is one thing. Getting a team of social workers or nurses or firefighters to sit down and talk to me is quite another. The concern here is that under the Care Act 2014, the Boards are the key mechanism for overseeing safeguarding practice, and should have robust systems for information and concerns to move up and down the chain from practice to strategic decision making. From my perspective, I cannot see this happening and, as a researcher, it is extremely frustrating.

However, having agreement and sponsorship from the Boards was important, and enabled me to then go ahead and contact all of the relevant organisations by email and begin liaison with the necessary gatekeeper.

5.7.6 Sampling strategy

I used non-probability purposive sampling, whereby particular people are chosen because they can provide important information based on their knowledge and expertise of the subject under investigation (Doody, Slevin & Taggart, 2013a). Inclusion criteria for the participants as stated in my ethics application were that 'participants must currently work with some people who self-neglect living in the community, or have past experience of working with people who self-neglect.

This may be in a paid or voluntary capacity, and they do not need to have a specific professional qualification (though many participants will have'). The word *some* was included to acknowledge and clarify that none of the participants were likely to be working solely with people who self-neglected, as I knew from initial fact-finding that there were no specialist agencies in either authority.

The intention is that purposive sampling will generate insight and in-depth understanding of the topic (Braun & Clarke, 2013). A disadvantage of purposive sampling is that the researcher may be inadvertently biased in selecting their sample (Gray, 2014). This is where information gleaned from my pilot study was very useful, in helping to ensure that I had identified the relevant professional groups, which had been identified by the participants as described above.

Reflexive stop-off

In one case I used opportunistic sampling (Gray, 2014). I had experienced extreme difficulty recruiting any doctors, whether working in primary or secondary care, to the initial cycle of the study, and indeed I was told by the research lead from one CCG that doctors would not have the time to participate (this situation changed during the next AR cycle). At the time I found this an astonishing response. However, subsequently, at a conference I met an A&E consultant who was very interested in patients who self-neglected. As he met the inclusion criteria for the study, I asked him if he would consent to being interviewed, which he did. Although this could be criticised for being a haphazard approach (ibid), I felt this was outweighed by the value of having another perspective represented in the study.

5.7.7 Initial recruitment to the study

The process of recruiting multiple agencies was extremely time-consuming and happened over a period of several months. In larger agencies, email information about the research was cascaded down from operational managers to team managers, who functioned as the gatekeepers to their teams, as a starting point. However, these emails generated very little response and as I did not have direct contact details for the gatekeepers I was in a very difficult position. If agencies were not directly represented on the Board (for example, Domiciliary Care Agencies) I made direct contact. In many ways, this was easier than having to negotiate the labyrinthine systems of the larger agencies. However, even here, despite initial enthusiasm from the gatekeeper, it could take many weeks before interviews took place with participants. These problems were not unique. D'Cruz & Gillingham (2017, p443) describe 'significant stress' in relation to problems with key organisations in regard to ethical approval and participant recruitment in their participatory research.

Reflective stop-off

It was during the recruitment stage that I began to discover the importance, for an action researcher engaged in professional AR, of building networks and developing allies (Gray, 2014, p336), which served me well in this and later cycles of the research. In some cases I was lucky to find people who supported me with recruitment, even though they may not have been directly involved in the research. For example, some weeks after the Board in Authority A, I was contacted by the Board manager who said she thought I 'might need some help with unblocking the system'. She did indeed provide that help, and remained a key ally during the remainder of the research. Similarly, in Authority B, the Research Lead of one of the Trusts was extremely helpful with contacts, suggestions, and in the second stage of the research, venues. On reflection, I do not believe that recruitment would have been anywhere near as successful without the help of these key people.

The following table and figures show the final recruitment numbers in the preliminary diagnosis phase, and the professional groups who were represented.

Table 7: Numbers of participants

	Authority A	Authority B
Number of participants	147	98
Group interviews	18	11
Individual interviews	7	6
Paired interviews	3	1

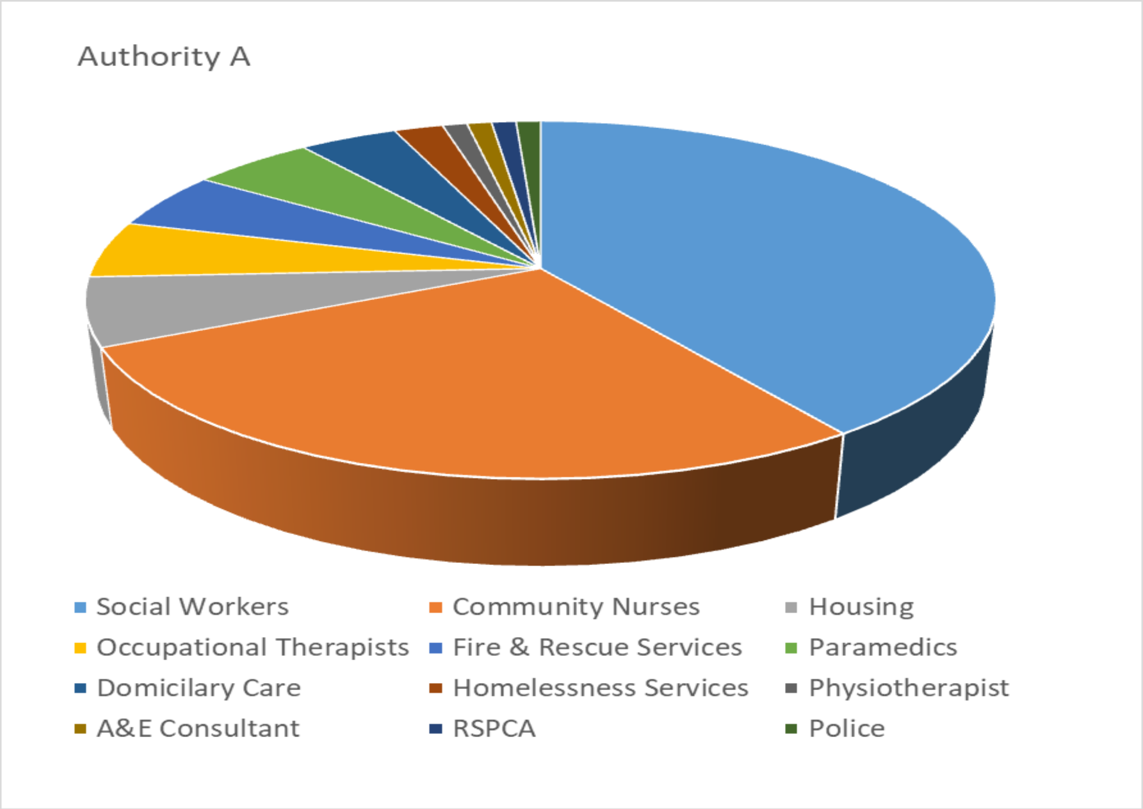


Figure 7: Participants by professional group, Authority 1

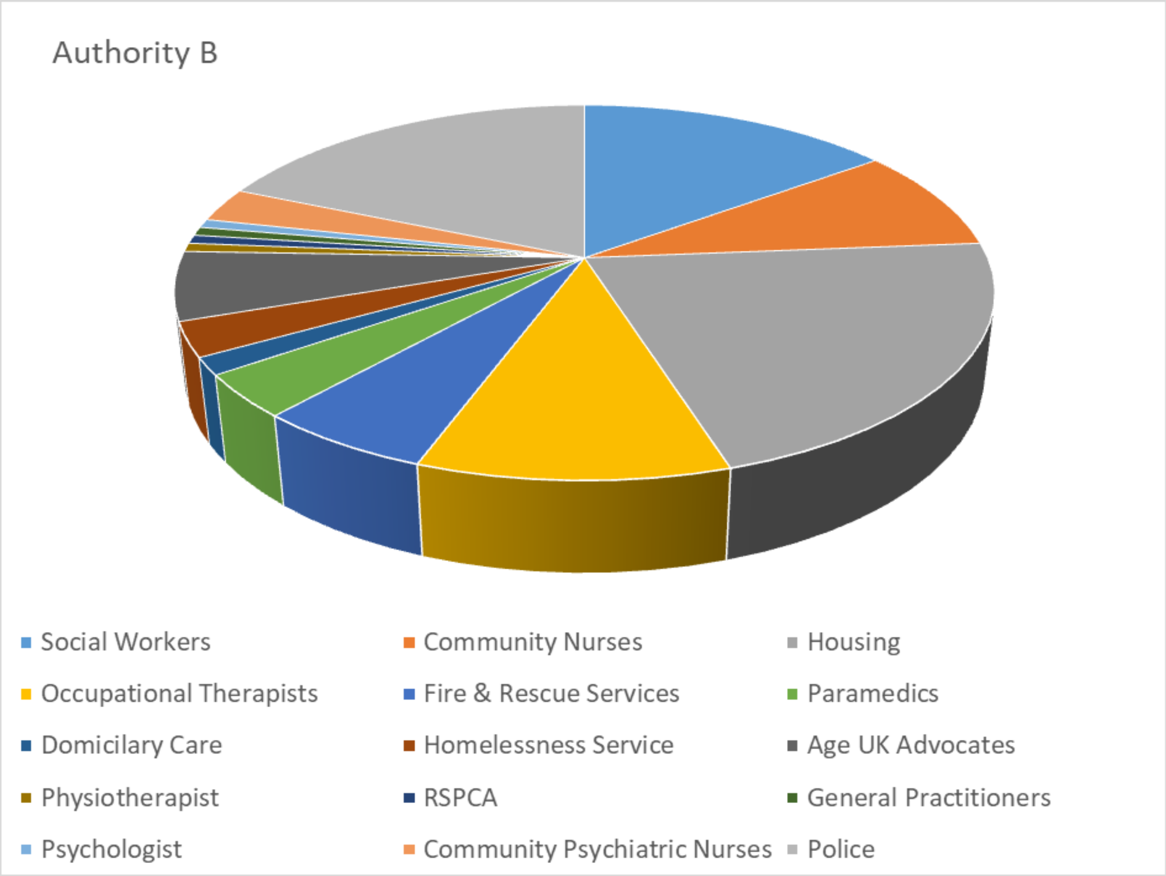


Figure 8: Participants by professional group, Authority 2

5.8 Preliminary diagnosis - Data collection

> The primary rule in action research practice is to be aware of the choices one is making and their consequences. (Reason & Bradbury, 2006, pxxvii)

AR does not prescribe any particular techniques for data collection, and Denscombe (2010) suggests that the techniques chosen are likely to reflect the background of the researcher. I sought, as far as possible to use techniques that were congruent with a social constructionist paradigm. I wanted to capture what Whelan (2007) conceptualises as 'epistemological communities … a group which shares a body of knowledge and a set of standards and practices for developing and evaluating knowledge' (p958). As O'Dell et al, (2016) describes 'epistemic communities articulate what is seen to be valid knowledge, legitimate experiences and claims to know' (p170). As many of my participants worked in teams, this led me therefore to one-off group interviews, which would allow me to access the interaction between participants and give me some insight into how knowledge in their particular setting was produced (Green & Thorogood, 2014) and meanings constructed *in situ* (Kamberelis & Dimitriadis, 2013). Morley (1980) argues that 'much individually based interview research is flawed by a focus on individuals as social atoms divorced from their social context' (p33). My hope in chiefly using group interviews was, as Gergen & Thatchenkery, (2004) so elegantly put it, to 'loosen the sedimented realities giving rise to "the problem"' (p245). Group interviews have been considered unsuitable when sensitive information is being sought (Doody, Slevin & Taggart, 2013a), although findings from Guest et al (2017) challenge this position. Their study found some types of sensitive and personal disclosures were *more* likely in a group setting than an individual interview setting.

However, I also had to acknowledge that some practitioners who work with people who self-neglect are not part of a team. These groups have tended to be excluded from research into self-neglect, yet may play an important role. They include animal welfare agencies (e.g. local RSPCA), and religious, charitable and voluntary organisations (e.g. local Age UK). I wanted to ensure that the perspectives of other groups who are involved in working with people who self-neglect were included in the preliminary diagnosis if at all possible, and thus I applied for ethical approval for both group and individual interviews. The two methods draw on similar techniques for data collection, 'open-ended questioning with inductive probing of responses' (Guest et al, 2017, p693). Triangulation of method by using group and individual interviews can both compensate for the shortcomings, and enhance the strengths of, both methods and is a component of credibility (Lincoln & Guba, 1985; Shenton, 2004; Lambert & Loiselle, 2008). However, there were also pragmatic reasons for using both (Lambert & Loiselle, 2008), as this was likely to maximise the number of participants. Guest et al (2017) argue that using both group and individual interviews is acceptable if the data collector, the instrument, and the interview environment are consistent across both methods. The first two were completely consistent, as I carried out all of the individual interviews and group interviews, and used the same question schedule for all. However, I did not have a consistent interview environment across either the group or individual interviews, as these took place in the participant's workplaces.

5.8.1 Terminology: Focus group or group interview?

Initially, I used the term 'focus group' to describe bringing groups together to discuss self-neglect and multi-agency working. However, informed by my reading and reflection, I realised that these were *not* true focus groups, and that this was a term applied rather indiscriminately in the literature (Kamberelis & Dimitriadis, 2013). Happell (2007) calls the use of focus groups a growing 'fad' (p23), noting that prior to 1985 there was no mention of the technique within the literature.

Focus groups, which are led by a moderator rather than an interviewer or researcher, were originally developed in the field of market research and were designed to elicit opinion about a product or topic (Madill & Gough, 2008). They have more recently been popular in eliciting opinion related to political policy (Stanley, 2016). Kamberelis & Dimitriadis, (2013) note that focus groups have been used as a way to 'get relevant, specific information from relatively large numbers of subjects quickly' (p3) which is rooted in positivist or post-positivist epistemologies, and assume that 'the Truth is "out there" to be efficiently excavated, reported and used'(ibid).

Green & Thorogood (2014), adapting the work of Coreil (1994) to health settings, distinguish four types of group interview,

Table 8: Types of group interview (From Green & Thorogood, 2014, p127)

Interview type	Features	Typical users
Consensus panel	Often composed of key informants or experts. Seeks group consensus or normative reactions. More narrow, closed-ended stimulus material	Agreeing clinical protocols, resource prioritisation
Focus group	Participants selected to meet sampling criteria. Seeks broad range of ideas of open-ended topic. Formal, controlled, pre-arranged time and place. Usually audio-recorded and transcribed for analysis.	Testing health promotion materials, exploring service users views
Natural group	Group exists independent of the research study. Format formal or informal. Interview guide loosely followed, Usually recorded by written notes	Ethnographic data collection (informal), social research (formal)
Community interview	Open to all or large segments of a community. Usually recorded by written notes	Project planning, programme evaluation

Although features of focus groups and natural groups are similar, key for me was the fact that I did not bring groups together to meet sampling criteria, but utilised established teams which adhered more to the definition of 'natural groups' (Green & Thorogood, 2014). This had advantages and disadvantages.

Reflective stop-off

I discovered that one drawback of using a natural group rather than a focus group was the difficulty in controlling group numbers. Ideally, a focus group consists of between 6-12 people. When arranging group interviews I always stressed this. In reality, it proved to be out of my control. I was often confronted with a group bigger than the prescribed and requested twelve. I had to make a pragmatic decision. Should I exclude people from the interviews in order to adhere to a maximum number? I felt that where people had decided to give up their time to discuss the topic, it would have been rude to try to exclude them, and risked setting up resentment towards me. As many of the groups had taken me a great deal of time and difficulty to organise, I felt that this would have been a very unwise course to take. Therefore, I did not exclude anyone from a group who had read the participant information sheet and signed the consent form, even if this made some groups a little unwieldy. Conversely, some groups were smaller than the prescribed six, perhaps because they were a naturally very small team, or because an emergency had occurred in the workplace, which meant that people who had anticipated attending had not been able to. Again, I made the decision to continue with the group who were there. In a few cases, I carried out paired interviews (Wilson et al, 2016) where this was appropriate. In summary, I worked with a wide range of interview participants and situations, and I believe that this pragmatic approach added to the thickness of the data (Bryman, 2016).

5.8.2 Group interviews and the 'ideal speech situation'

Greenwood (2015, p202) argues that in Habermasian terms, bringing a group together in this way creates an 'ideal speech situation' which is central to AR. Habermas (1970) defines ideal speech as 'intersubjective symmetry in the distribution of assertion and dispute, revelation and concealment, prescription and conformity among the partners of communication' (p371). Despite criticism that has been levelled at the possibility of achieving ideal speech situations (Greenwood & Levin, 2007; Jeffries, 2016), Greenwood (2015, p202) nonetheless argues that action researchers must believe that conversations which allow all voices to be encouraged and heard can be had, and that it is the researcher's responsibility to facilitate this 'ideal speech situation'.

Habermas (1979) describes the four fundamental conditions for effective communication as being that the speaker must be comprehensible, they must speak truthfully, they must be trustworthy in what they say and they must express themselves appropriately for the listener. I found it extremely helpful to consider these conditions, during the first data-gathering phase and the subsequent cycles of the research. Was I sure that people always understood what I was saying? What was the perlocutionary (Austin, 1962) effect on the receiver of the questions that I was asking? How did I ensure the veracity of any information I was giving? How could I demonstrate sincerity in all of the encounters I had with the many professional groups? The exercise of writing the ‘researcher identity memo’ (Maxwell, 2013) described above, helped me to reflect on what my ‘hidden agendas’ might be, and how I could strive to minimise them. Many of the considerations of methods used, described in this chapter and subsequent chapters, related to appropriateness, making sure that what I was doing and what I was asking was respectful and understanding of the participants involved. Where I was dealing with situations of status and power differences between participants, or, as in the later cycles, differences between professional groups, this was not always easy.

5.8.3 Homogeneity vs Heterogeneity

The purpose of the natural group (Green & Thorogood, 2014) interviews was to identify each disciplinary perspective, share and explore experiences, and understand the changes that participants may wish to begin to implement (Eady et al, 2015). The aim was to identify the key occupational differences, as espoused by practitioners, and understand differences in language and agenda among the professional groups.

Using natural groups of different professionals meant that homogeneity of profession was obtained in this exploratory phase. Gray (2014) notes that the rationale for separate homogenous groups is that a wide range of viewpoints is more likely to be revealed if participants are sufficiently confident with one another, and Kahan (2001) suggests that homogeneity helps groups generate interactions, both key factors in the initial stage. It was interesting to discover, as the recruitment unfolded, that multi-disciplinary teams were still highly unusual in both of the authorities in which I was researching. I had only one experience that was not with a homogenous team.

Journal entry
The decision to run uni-professional focus groups was a good one though, because on the one occasion where the group was multi-professional, I felt that the effort by practitioners to be respectful of one another, led to obfuscation and circumspection, and much biting of tongues. It will be interesting to compare the transcript from this group with others.

However, what the groups lacked in many cases was homogeneity of professional status. Several authors note that the researcher should consider that power differentials within a group may inhibit participants from expressing their thoughts and opinions openly (Shenton, 2004; Happell, 2007; Doody, Slevin & Taggart, 2013a). It was not just that in many cases there was a manager present, but also that there were differences of bandings, job titles etc., of which, as an outsider, I did not fully comprehend the significance. However, I felt it would have been unrealistic to exclude managers (who would be wondering what their team would say about them), or specify that only certain bands or grades of staff should attend.

Journal entry
Thinking about the influence of managers in the focus groups, and wondered whether these groups were not an opportunity for managers to ‘guide’ their staff, and talk about their own philosophy, or the best way of doing things. For visibly less experienced, younger teams that I came across, maybe this was important. A manager of one team told me she was pleased to have the opportunity to discuss mental capacity with her team as part of the group interview, as this was an issue that made them very anxious.

I also observe that in many groups, less formally qualified members of staff often have considerable years of experience, and were clearly able to be very vociferous, and sometimes more challenging in the discussions. Having a manager in the group did not necessarily hinder discussions.

Ultimately I concluded that managers, for example, were part of the ‘natural group’ (Green & Thorogood, 2014) of a team, and therefore should be included. It was some of my responsibility, in facilitating the groups, to try to make sure that everyone was heard.

5.8.4 Running group interviews: proxemic considerations

As I had relatively little experience of running group interviews, I turned to the literature for guidance about good practice in facilitating group interviews. However, as Puchta and Potter (2004) argue, the literature provides little on the moment-by-moment business of bringing groups to life and managing the various troubles and opportunities that arise. Instead, they argue, the literature tends to be too abstract or too prosaic, assuming that the researcher will be able to take this role and do all this quite easily. Puchta & Potter (2004) argue that whereas in marketing focus groups the moderator has little personal stake in expressed views, in social science research the researcher may have an important stake, in setting the focus of the group and steering the discussion (Puchta & Potter, 2004).

One important consideration for me was that as I was utilising natural groups, and as I was visiting the workplaces of my participants, the group interviews always took place in physical spaces that were completely unfamiliar to me, yet very familiar to the participants. I was entering semiotically rich environments, which told me much about the culture of the teams and the organisations (Trice & Beyer, 1994). These included open plan offices, meeting rooms, boardrooms and surgeries, which were often too small to hold comfortably the number of people attending. Hall (1966) divides spaces into the sociopetal and sociofugal. Sociopetal spaces encourage interaction and communication, sociofugal spaces discourage them. Many spaces I held group interviews in were highly sociofugal - cramped, hot, squashed, uncomfortable, and airless – but often these would be the only spaces available to a team, and the one where all the important gatherings took place.

Reflective stop off

Though I was in strange territory, it was my responsibility to make the group 'work' profitably, and I found this very difficult. Reflecting after the first few groups why this should be so, I realised that I often felt uncomfortable, embarrassed, and nervous in the group interviews. I could not understand why this should be. I didn't feel like this when I was teaching or running seminars.

The seminal work of Hall (1966), recently updated by Sorokowska et al (2017), on proxemics seemed to offer some way of understanding my experiences and feelings. Hall (1966) described the idea of proxemics, 'the region surrounding each person, or the area that a person considers his or her domain or territory' (p34). Hall proposed that all humans have at least some personal space requirements, and that we use distance-setting mechanisms of which we are generally not aware. He posited that there were four types of domains, which could be measured (see diagram below). Sorokowska et al (2017) note that 'people may feel intruded upon and react negatively when others adopt and maintain too close of a personal distance' (p579).

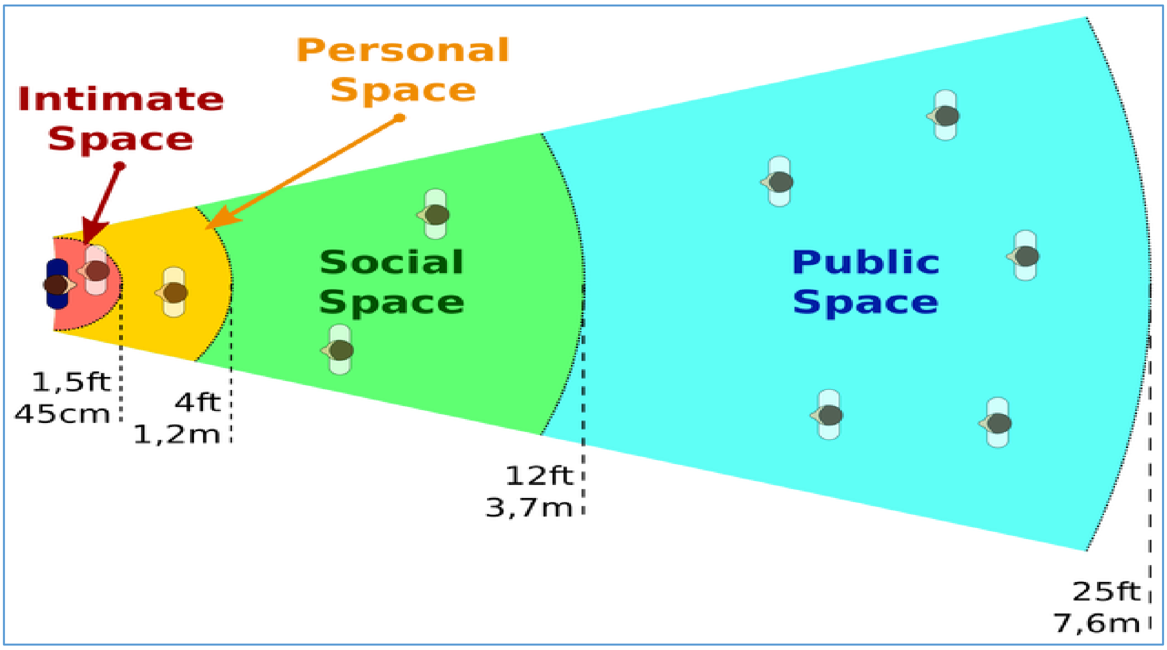


Figure 9 : Hall's Typology of Personal Space (Image Jean-Louis Grail, 2011(CC BY-SA 3.0) via Wikimedia.org)

Hall (1966) divides social space into close and far distance, and argues that people who work together tend to use close social distance, between 4-7 feet. Lecturers are usually operating in the public space, which places the emphasis on loud voice and body movements, where eye contact is minimised. Hall (1966) also distinguishes between 'contact' and 'non-contact' cultures, contact cultures being countries where people used closer interpersonal distances and engaged in more touching, which were generally hotter countries.

Sorokowska et al's work (2017) has confirmed and extended Hall's work in relation to social distance, particularly in relation to cultural differences. Sorokowska et al's study (2017) also found that age and gender were important. Women in their study preferred wider interpersonal distances than men, and age was a significant predictor of personal and intimate distance – younger people prefer closer distances. They confirmed that the hotter the annual temperature of the country, the closer people preferred to get (ibid, 2017). As an older woman from a non-contact, generally cold and wet weather culture, this meant my 'proxemic bubble' (Hall, 1966) could be seriously compromised by being too close to people, causing my blood pressure and heart rate to rise and increasing my levels of anxiety (see Appendix 6 for visual examples). I also reflected on the implications of these proxemics challenges for my participants.

- In all cases, the participants all knew each other to some degree.
- In proxemic terms, in the course of their work, they generally occupied each other's social space.
- In most group interviews, they were forced to occupy each other's personal space to some extent.
- I didn't know them at all, but rather than occupying a comfortable public space, in many groups I occupied personal space with them.
- Sometimes where rooms were small, we occupied the same intimate space.

There is perhaps a contradiction here in relation to proxemic challenges. As mentioned above, one of the important reasons for carrying out group interviews rather than individual interviews is to stimulate and capture conversation between the participants. However, there is a risk that the proxemic issues within an interview setting may make this dynamic less likely. Despite these reservations, my experience was that when group interviews worked, they yielded spectacular results, as the following journal entry shows,

Journal entry

Did a group interview today. All squashed into their communal office, which was already very cramped to start with. People dragging in chairs from other rooms, phones ringing, sandwiches being eaten, people having to leave, other people arriving. Yet they all talked, all engaged, were so passionate about what they did, frustrated by how the system was working, how powerless they sometimes felt. The discussion rather ran itself, and they had loads of good ideas.

5.8.5 Recording the interviews

The use of audio recording has generally superseded the writing of notes in research interviews (Tessier, 2012), and I made the choice that all of my group and individual interviews would be audio recorded for convenience. However, in practice I was surprised to observe how constrained participants were by the data recorders, which had to be placed in a visible position for maximum effectiveness. I reflected that the very act of recording might be tempering what people were willing to say, and that although taking written notes would have captured far less of the discussion, it may have made people speak more freely if they had the reassurance that they were not being recorded. Although constraint lessened as the interviews progressed, people often referred to the fact that they were being recorded. This could be as a source of fear about recriminations, as if they had given away something of themselves to me which I could then use against them as it were,

> I'm very pessimistic about the government and things like that. You're not going to give this to Big Brother are you? (Community Nurse)

or as a feeling that they were speaking out of turn or saying too much,

> R1 ... shall I shut up? Is it alright to say now?
> Me: Yes of course
> R2: Don't put that in!
> R3: He's on his soapbox now (Community Nurses)

One participant when discussing how his service operated, mentioned 'Chatham House rules, I know you're recording it'. This created an ambiguous situation in that he had given his consent to be recorded, but clearly this was limited consent in his view. Interestingly, one of his colleagues then jokingly identified the speaker 'for the purposes of the tape', as if to ensure the veracity of the recording. These participants were constructing the situation differently from me. Thus, using audio recording has already begun the process of constructing the data in particular ways.

5.8.6 Transcription considerations

As Poland (1995) describes, the act of transcription is itself an interpretation, and it is arguably the initial stage of analysis (Kvale, 2007: Tessier, 2012). Calling a transcription ‘verbatim’ still raises many questions about the trustworthiness of the final transcription. Kvale (2007) posits that ‘transcripts are impoverished decontextualised renderings of interview conversations’ (p93). One reason for this is that they do not reflect body language, eye contact, or breathing, in short the somatic challenges that I was experiencing. On reading the transcript I might ask myself in frustration why I phrased a question in a particular way, because the transcript could not give me a sense of what else was happening, whether people were making eye contact with me, if anyone was fidgeting and looking bored.

Kvale argues that all transcriptions are constructions, that there can be no ‘objective transformation from the oral to the written mode’ (p98). For Kvale, the most useful question for researchers is to ask what a useful transcription for one’s own research purposes would be (ibid). Kvale (1995) also argues that a strict verbatim transcription, for example, in the Jeffersonian style (Jefferson, 2004), where every utterance, filler, background noise etc. is included, can risk making the participants seem incoherent and inarticulate. I decided that because I was not studying the interaction between the participants on the micro-level, ‘intelligent verbatim’ style (Salonga, 2018) would be sufficient.

Reflective stop off
It was not until I came to transcribe my recordings that I realised how many decisions there were to make about how the transcription was constructed, and the extent to which transcription was an interpretive act. This was where the permissive nature of AR was a frustration. AR prescribes no techniques for data analysis, or indeed for transcription. Yet I came to realise that making decisions early on in the research process about how data is going to be analysed not only affects how that data is collected, it will also affect the style of transcription. I had to continually paraphrase Kvale’s question above and ask ‘what is the most useful way of doing this particular part of the process, for my research purposes’. Ultimately I concluded that for this AR project, I did not require detailed linguistic conversational analysis, but the reporting of ‘subject’s accounts in a readable public story’ (Kvale, 2007, p95)

5.8.7 Confidentiality & Anonymity

In a professionalising action research study such as this, it is necessary to be fastidious about maintaining confidentiality and anonymity in several respects (Guenther, 2009; Green & Thorogood, 2014). However, this may have implications for the study itself, particularly when using a participatory approach. As Guenther says, 'the decision to name or not to name is rife with overlapping ethical, political, methodological, and personal dilemmas' (2009, p412).

Firstly and obviously, it was very important to maintain confidentiality around who had actually taken part in the interviews (despite some pressure to disclose this, from one manager). This was not just in relation to individuals, but also to teams, particularly in smaller organisations. I had to be vigilant about this. In group and individual interviews, I asked for the minimum of demographic information from participants (first name and job title), and names were not used in transcripts to ensure individual anonymity. However, Guenther (2009) warns that confidentiality may give researchers the feeling of complete protection, and encourage excessive candour, which may still leave participants open to identification.

Secondly, during the interviews, participants often spoke of cases they were, or had been, involved with. In many descriptions, these presented fascinating examples of practice with people who self-neglect. One case was mentioned by three different teams working in the same district. Although I always asked participants to try to avoid using names, in the flow of conversation they often forgot. This meant that names and details of individual service users appeared on recordings. I tried to be rigorous about removing identifying features from transcripts. It was though, very tempting, some would say obvious, to use the case examples in further research cycles (anonymised of course), as they were clearly directly drawn from real life, and were clearly good examples of problematic multi-agency working. However, I felt that ultimately the people who were being talked about did not know and had not given permission for their case to be discussed. However heavily they were anonymised, the cases could still potentially be recognised, and I chose not to use their stories further in the research. They were not my stories to tell. I will return to the issue of using 'live' case studies in a later chapter.

Thirdly, when I began to analyse the data, it was clear that I would have to be very careful to retain anonymity around 'who had said what about whom'. This would apply when sharing data with participants in subsequent phases of the research, and when negotiating participation in further stages of the research by their employing organisations. As noted earlier in this chapter, AR depends on the 'careful initial building of relationships and negotiation of roles' (Herr & Anderson, 2015, p114), and having invested much time and effort into doing this, I did not want to inadvertently fuel further discord. However, as Guenther (2009) writes, there is a risk that by ensuring anonymity the voice of participants is lost, that the researcher may be guilty of 'silencing their challenges of systems of oppression and injustice'. These were considerations that I returned to at each stage of the research, and will be discussed further in subsequent chapters.

5.9 Data analysis considerations

I decided I would use NVivo software to help organise my data corpus, as using such programmes may be a way of contributing to the trustworthiness of results (Bazeley & Jackson, 2013). Discussion in supervision, and the process of becoming more familiar with the data corpus through repeated reading, made me realise that I had not thought carefully enough about which type of data analysis was most suited to the research. This led me to consider my justification for choosing a particular approach, and the 'fit' with both a relativist, social constructionist ontology and an action research orientation. Sagor (1992) notes that:

> Data analysis can be most simply described as a process of sifting, sorting, discarding, cataloguing in an attempt to answer two basic questions: are there important themes in this data, and how much data supports each of these themes? (p48)

However, this apparent simplicity is obscured by a multiplicity of available methods. Madill and Gough (2008) for example, list 32 methods of qualitative data analysis. Although many qualitative research methods suggest specific forms of data analysis, (Bloomberg & Volpe, 2016), there is no prescribed form of data analysis for AR, and, as Andrelchik (2016) points out, ‘one of the many challenges associated with action research is knowing how to analyse and interpret data’ (p135). As Winter & Munn-Giddings (2001) note, methods which may be more widely used in qualitative research to analyse data may not be a good fit with the overall structure and relationships of AR. They give two reasons for this. The first is that in-depth analysis of the data by the researcher will prevent participants from being able to offer alternative explanations, and thus the more elaborate the researcher’s analysis, the greater the risk that the opportunity for collaboration is lost. They suggest that a way to mitigate this is to ‘treat our first coding of the data as further data, to be circulated for others for comment and suggestion’ (p237). The second reason is that:

> The more we try to reduce the data to manageable proportions, the more we tend to use our original set of concepts as criterion of relevance, and thus exclude respondents’ ideas. But … the more we try to include ideas from respondents which were not part of our original framework, the more unwieldy becomes our analysis (ibid).

Faced with this dilemma, it is tempting to employ the principle of bricolage, to move between different ways of analysing data (Kvale, 2007). Kvale argues that interviews can be analysed in this way, ‘without following any specific analytical method’ (p115). However, I felt that there was a risk this could compromise data trustworthiness, and result in confusion.

5.9.1 Using thematic analysis

I finally concluded that thematic analysis (Boyatzis, 1998; Braun & Clark, 2006) was the best option for this research as it appeared to offer a degree of flexibility, whilst avoiding analytical confusion. It is a method which lends itself to a constructionist epistemology, in seeking ‘to theorise the socio-cultural contexts, and structural conditions, that enable the individual accounts that are provided’ (Braun & Clarke, 2006, p14).

Braun & Clarke (2006), the main contemporary proponents of thematic analysis, believe that it is flexible, accessible, and useful both for a participatory research paradigm and for a large data set. Of particular interest to me is their argument that thematic analysis is useful in the areas of policy and practice, because it can be used to organise and present data in an easily accessible way for non-researchers (Braun & Clarke, 2014). For participatory data analysis, which I wanted to explore, this seemed an important consideration. However, thematic analysis may be criticised for its very simplicity and perceptions that it is somewhat unsophisticated, as Braun & Clarke (2014) acknowledge, though they argue that this view represents a misunderstanding or misapplication of thematic analysis. There are 6 phases of conducting thematic analysis (Boyatzis, 1998; Braun and Clarke, 2006): familiarisation with the data through transcription and repeated reading; open coding; searching for themes; reviewing themes; defining and naming themes; and interpretation of themes, though it is misleading to suggest that this is a linear process, particularly in the later stages.

A theme 'captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set.' (Braun and Clarke, 2006, p8). Willig (2012) suggests keeping the research questions in mind and being modest about what the research can reveal, ensuring that the participant's voice is not lost, and remaining open to alternative interpretations.

5.10 Conclusion

In this chapter I have endeavoured to describe the process of conceptualising, negotiating and beginning to address the problem at the centre of the study, namely 'how can professionals change the way they work together to improve outcomes for people who self-neglect?' As summarised by Sandars and Waterman (2005) at the start of this chapter, the process I have described, in an AR study, is then ‘followed by planning and delivery of an intervention, which in turn is followed by more fact finding or evaluation’ (p294). In the next chapter I will consider how I proceeded with analysis of the data generated by the group and individual interviews, what the analysis began to show, and how findings from the data were used in the planning and delivery of the next iteration of the AR cycle.

Chapter 6: Findings - The problem-sensing phase

6.1 Introduction

In the previous chapter I detailed how I conceptualised and planned my research in its first phase, leading up to carrying out the group and individual interviews. In this chapter, I will continue to explore this problem-sensing phase (Hart & Bond, 1995), by discussing the findings from the interviews. I will describe how the findings enable me to begin to plan the next AR cycle.

The writing up of my data analysis journey imitates the temporal sequence of its occurrence, in that data collection, transcription and data analysis were often undertaken concurrently. Group and individual interviews in the two local authorities took place over a period of months, during which time I was also transcribing recordings and beginning initial data analysis of interviews already completed. It was both a reflexive and an iterative process (Fereday & Muir-Cochrane, 2006).

6.2 Data analysis within the AR cycle

> Qualitative researchers often refer to ongoing data analysis but in AR, there is virtually no choice since it is imperative for the process. (Herr & Anderson, 2015, p90)

I felt overwhelmed by the amount of data that I had generated, and the need to be able to produce feedback to participants and their employers relatively quickly, so that the research could continue into further AR cycles. Carrying out of the interviews did not represent the end of the involvement of the participants, as it would in other forms of qualitative research, but rather that I hoped that my participants would want to carry on the research journey with me.

I believe that there is a dilemma for an action researcher involved in professionalising action research (Hart & Bond, 1996) because of the cyclical nature of AR. This is that some data may need to be fed back to the participants (and gatekeepers) reasonably rapidly, because of the very nature of the research orientation, and to maintain the interest and involvement of participants. However, as the data collection process is itself an iterative and incremental one, the time available for analysis of the data corpus may be quite limited. Because I had a large volume of data, I needed a way to be able to work with it quite quickly to produce feedback, whilst continuing a more in-depth exploration.

Reflective stop off

Not unreasonably, both the safeguarding boards who were key to taking the research further had contacted me to ask for an update a few months after I had started the interviews. Already a fair amount of time had elapsed, and I was at risk of losing any momentum and interest that had built up. However, with so many different agencies involved, the recruitment and interviews took place over a period of several months. I felt that I could not ask the boards to give me a month or two to 'do' data analysis and finish the interviews without giving them some feedback. The boards only met quarterly, so I had to be mindful of providing them with timely information to gain permission to continue with the research and to not leave myself unable to proceed for months at a time.

I decided that initially, because of the pressures described, I would employ selective coding on a particular data set from the wider corpus. Braun & Clark (2013) suggest that coding can be on two levels, the semantic and latent. Semantic codes, or data-derived codes provide an explicit and succinct summary of the content of the data, whereas latent codes (or researcher-driven codes) 'invoke the researcher's conceptual and theoretical frameworks' (p207). For feedback to the group who would be taking the AR to the next stage, it seemed appropriate that it was semantic data that was reported back, 'mirroring participant's language and concepts, without an 'interpretative frame around their words' (ibid). Lyons & Coyle (2016) make a distinction between inductive and deductive analysis. Inductive analysis begins with the data, which are considered in relation to the research questions posed by the study. This is sometimes referred to as 'bottom up' because it involves starting with the specific (the data) and moving towards the conceptual and theoretical levels. Although Willig (2012) states that 'qualitative data always involves interpretation, whichever analytic stance is taken' (p45), I still felt this approach was valid. Essentially, this was 'diagnostic data' – what people had told me about what they saw as the changes that were needed – that would enable the action research to progress. This is in line with McNiff (2017) who suggests that for AR, data can be analysed from both a surface-level factual perspective and a deep-level meaning-making perspective. It also answers Winter & Munn-Giddings point (2001) referred to above, about the danger of carrying out in-depth analysis of the data at this point which did not incorporate any alternative explanations from participants. I wanted my participants to be part of the data analysis in the next cycle of the research, so it was not appropriate for me to over-develop the themes – I felt that the 'domain summaries' or 'bucket themes' (Clarke, 2017) were what was needed to give feedback for consideration and analysis by the Boards.

6.2.1 Developing the 'Headlines'

The key information which could be helpful at this early stage was the data set for the question 'What do you think could be changed in the way we work together to improve support people who self-neglect?' I therefore used the responses from this 'change' question to develop a simple semantic, essentially inductive, set of codes, supplemented by some direct quotations from participants, and summaries where this was appropriate. I did not, at this point, give any priority to the number of times a potential change had been mentioned by participants in the interviews, as even if a point was only mentioned once, it could still be very meaningful (Braun & Clarke, 2016). I termed these response codes 'Headlines', as I felt this term would be more accessible to both the safeguarding boards and participants, and gave a sense of importance and urgency as in 'headline news'.

Headlines: 'What do you think could be changed in the way we work together to improve support people who self-neglect?'

- **Improved awareness of each other's roles** - 'all professionals need to be going shadowing each other, because you don't know what their responsibilities are, what their roles are, if you haven't had the opportunity to spend time with them. That should be available for everybody', 'people knowing what you do and, more importantly, what you can't do and why you can't do it'. A mechanism for keeping those links alive', 'a day placement with social services'

- **Communication** – 'We have to be less precious', 'pull together, not try and pinpoint the blame to 'you should do this' and 'you should do that': 'having a system where you are communicating better between those agencies and vice versa for them to tap into us because we have equally as much information to give someone as they might have': 'stop thinking 24 hour care is the answer to everybody's problem, because it's not'

- **Multi-agency training** - Needs to be carefully structured so it's not 'them and us': Specialised training about self-neglect, and about capacity: 'If we had training then everyone would have the same message and that clear focus when we go out to people, that this is what we should follow, and this is the standard we should act on in certain situations': 'what even is self-neglect and do we all know what areas we're looking at really?': 'self-neglect training that just brings people into the forum, that everybody's got a responsibility because of the Care Act'.

- **More meetings, getting everybody together, early reviews**, 'being more pro-active before things reach crisis point': 'all get together and nip it in the bud': 'I think people work in isolation too much, until it hits crisis point': 'so that at least everything possible has been discussed, offered, and then if the worse thing happens, then at least everything was tried': 'something in-between care management and safeguarding'

- **Multi-disciplinary team decisions**, 'rather than one agency getting lumbered': 'they all share the information, they all do their bit, so not one person's left with everything, make sure nobody's duplicating': 'Deciding who 'owns' complex cases': 'there's got to be more collaboration because at the moment agencies are getting further and further apart'

- **More integration of private care agencies** into 'the system', more development of shared care, working with agencies. Particular agencies allocated to particular nursing teams for example. More interaction with the police.

- **Making it easier to refer to other agencies** – e.g. a phone call being enough, rather than asking other agencies to refer via customer services, or complete a lengthy form, 'I say, I need to speak to someone, and they're all 'mumble, mumble, don't look at him': 'you put the call in, it's like 'no, not known to us', 'well, I'm telling you now', 'well, fill out a form': 'getting past the gate'. Accessibility, 'being able to actually have that conversation on a regular basis'. More information on referrals. Streamlined referral system.

- **Timescales** and monitoring performance. The same kind of accountability across services, in terms of delays and timescales.

- **A way of escalating cases**, getting a 'super-fast response' (particularly where a person has lost capacity). 'If other agencies are involved, they all get pinged or texted to say they've got to contact the patient within a certain timescale': 'that fast track'

- **A streamlined process** - linked communication where there are concerns. A clear framework, the same outcomes. Examining where one part of the system falls down because of another part. Clear boundaries about confidentiality

- **Documentation** – much more specific paperwork about how the person's capacity has been assessed/ an algorithm type assessment, a checklist that could be followed by all, some idea of where other people draw their line in self-neglect cases. 'A good design of a quick to complete capacity paperwork': 'a certain framework that everyone could work to': 'an admission checklist for self-neglect to be something you consider', 'making self-neglect a specific area on the care plan': 'you could ping it into your assessment'. Good support plans, good documentation. Information sheet, leaflet.

- **A mechanism to protect staff** if a person refuses services (makes an unwise decision) – similar to what happens when someone self-discharges from hospital, or refuses to go into hospital with a paramedic.

- **A care co-ordinator for self-neglect cases**, 'somebody who gets the whole picture, who is strong enough to hold it together and keep everybody else informed. You need somebody to grasp that nettle': 'a port of call, a person you could go to': 'they need somebody managing their care because these people have got multi factors going on, they do get lost in the ether, they need care co-ordinators'

- **All on the same IT system** – all sorts of issues, people having to use two, three or four systems, having to ask other professionals to go on 'their' system, because they don't have access, just utter confusion about the different systems, what has to be recorded, who can access what.

- **Better demographic data** – 'how many people in a service are 85+, or have a learning disability, or an addiction issue, or are morbidly obese, or have a mental health problem'

- **Low-level support service for self-neglecters** – this would reduce the need for bigger packages of care, reduce the number of cases going into crisis. 'you need a lesser form of support for them, like pro-active support to stop them getting to that stage'': 'for somebody to step in that's not going to issue them with a notice or section them or anything': 'peer mentors'.

- **Continuity and consistency for the service user** - 'you get to know that person, you get to know their background, you get to know their childhoods, you get to know why they're at that point': 'more focus on the individual, rather than 'I can only do this or that and no more''.

- **Money – '**More money, more services, more support workers': **'**Money coming out of the same pot, rather than the fighting over who is responsible'

- **The way that people are defining capacity** – inconsistent, nonsensical. Getting a self-neglecting person to demonstrate that they can manage- consistency needed on this from all agencies

Reflective stop off
Although the Headlines do give a strong flavour of what participants were actually saying in the interviews, they were compiled somewhat against the clock, and perhaps some nuance was lost because of this. However, the strength of the Headline data lies in the fact that these headlines were all generated by the participants and reflected their priorities rather than those of their managers or employers, or me as the researcher. Sometimes an idea for change would emerge from a part of the discussion earlier. So, for example, a discussion about not understanding each other's roles, might then lead, to a suggestion for change like 'as we were talking about earlier, we need to know more about what each other does'. In other cases, the idea was new and had not been discussed previously in the interview. In compiling the headlines, I was trying to reconcile various pressures, and ultimately had to make a pragmatic decision about what to do to be able to move the research on.

Thus, at this early point in the process, with the need to feedback some information to the safeguarding boards, I met with the key personnel in each area, to discuss the 'Headline' data (fully anonymised). In LA1 I did this with the head of safeguarding and the safeguarding board manager, in LA2, with the lead safeguarding nurse and a consultant from public health, who had become interested in being involved in more depth in the research. In the next chapter I will discuss the outcome of these meetings. But for the remainder of this chapter I will discuss the further analysis of the data corpus, key parts of which heavily informed further AR cycles both directly and indirectly.

6.2.2 Developing themes

I was using both deductive and inductive analysis (Lyons & Coyle, 2016) in this stage. Analysis was deductive in that it was informed by theory and the literature in the discrete areas of multi-agency working and self-neglect. However, analysis was also inductive as it was driven by the data emerging from the interviews themselves as they went along.

I developed an initial set of codes and themes. However, discussion in supervision caused me to reflect on the risk that I was shaping the analysis to fit my prior beliefs and assumptions, and having developed an initial thematic map, was tending to ‘slot’ data extracts into particular codes, rather than paying close enough attention to what the data were telling me. I began to feel that a deductive approach to analysis may encourage this narrow minded approach, and could mean that my ‘findings’ were simply confirming what the literature already said. However, I felt that in elements of my analysis which were more inductive, I was potentially prone to what Bryman (2016) has referred to as ‘anecdotalism’, where one or a few instances of a phenomenon are reified into a pattern or theme, when it or they are actually idiosyncratic. Neither seemed particularly complementary to an AR approach. As Braun & Clarke (2006) note, discussion of themes ‘emerging’ or ‘being discovered’ is a ‘passive account of the process of analysis, and it denies the active role the researcher always plays’(p7).

Brinkmann (2014, p722) suggests that there is an alternative to the ‘inductive collector’ and the ‘deductive framer’. That is abductive analysis, which is ‘concerned with the relationship between situation and enquiry… the goal is to be able to act in a specific situation (Bloomberg & Volpe, 2016, p191). Brinkmann (2014) uses the image of the researcher as bricoleur (mentioned in previous chapters in relation to AR) or craftsperson, and draws a strong parallel with abduction and pragmatism:

> The goal of the abductive process is not to arrive at fixed and universal knowledge through the collection of data. Rather, the goal is to be able to act in a specific situation. A “situation,” according to the pragmatists (Peirce, James, Dewey), is a result of a breakdown in understanding, when the person (or collective) is unable to proceed’ (p722).

It seemed to me that this ‘breakdown-driven’ (ibid) approach offered something to me as an action researcher, where the focus in on the ‘problem’, exploring an area where ‘breakdown in understanding’ (ibid) was a key issue. Brinkmann (2014, p722) explains that abductive analysis is driven also by ‘situations of surprise, bewilderment and wonder’. It is asking the researcher ‘what are you surprised by?’

Reflexive stop-off

If I am taking seriously my own subjectivity here, there is surely a question about how difficult it is a researcher to say 'that doesn't quite agree with published literature' or 'that doesn't quite agree with my participants' – these are the two sources to treat as sacrosanct. However, then I need to trust the researcher's instincts, and to be able to say, 'Because I find that curious'. In practice, I used a combination of deduction, induction and abduction. In some instances it was important to see how my findings aligned with existing research, in others to be paying attention to ideas, feelings and frustrations that were being expressed. Therefore I believe that considering what I was surprised by was also key in being able to move the research forward in to the next cycle, and ensure that the issues taken forward had real meaning for the participants and held out the possibility of change.

Having carried out over 30 group and individual interviews, I had a great deal of data. Wolcott (2009) writes research data requires 'constant winnowing', to discover 'the essences' of what is important, in order to avoid becoming 'buried by avalanches of our own making' (p35). It is this essence that I tried to capture in the six themes I eventually arrived at:

- How self-neglect is understood
- My job
- Their job
- Getting on together
- We don't always get on
- Can we try to change it?

I have tried throughout to keep the naming of codes and themes simple and as close to the participants' own language as possible (Philipowsky, 2018). A map of themes (global, organising and sub-themes) and an example of the codes for the 'change' theme are given below.

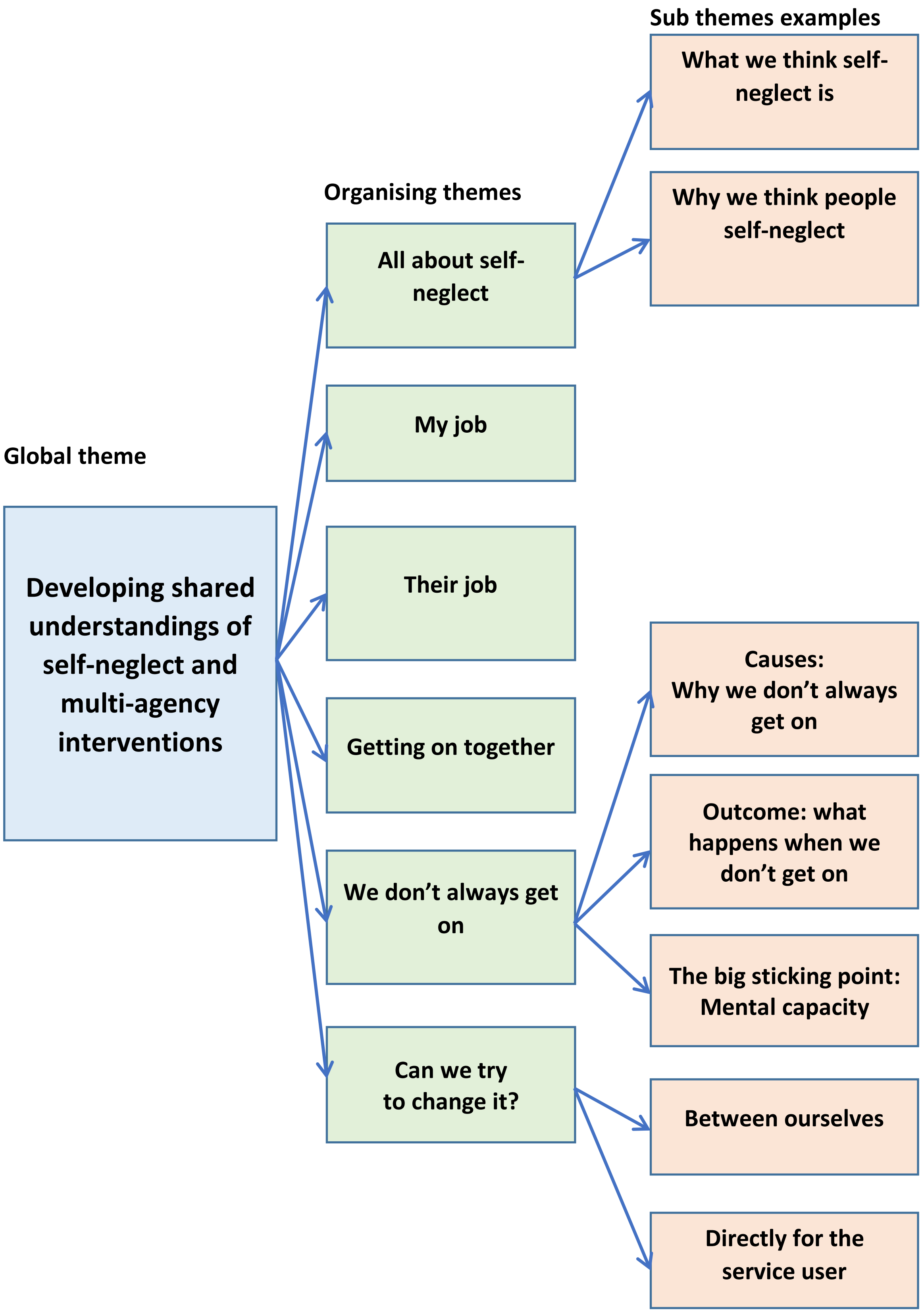


Figure 10: Thematic map, global theme, organising themes and sub-themes

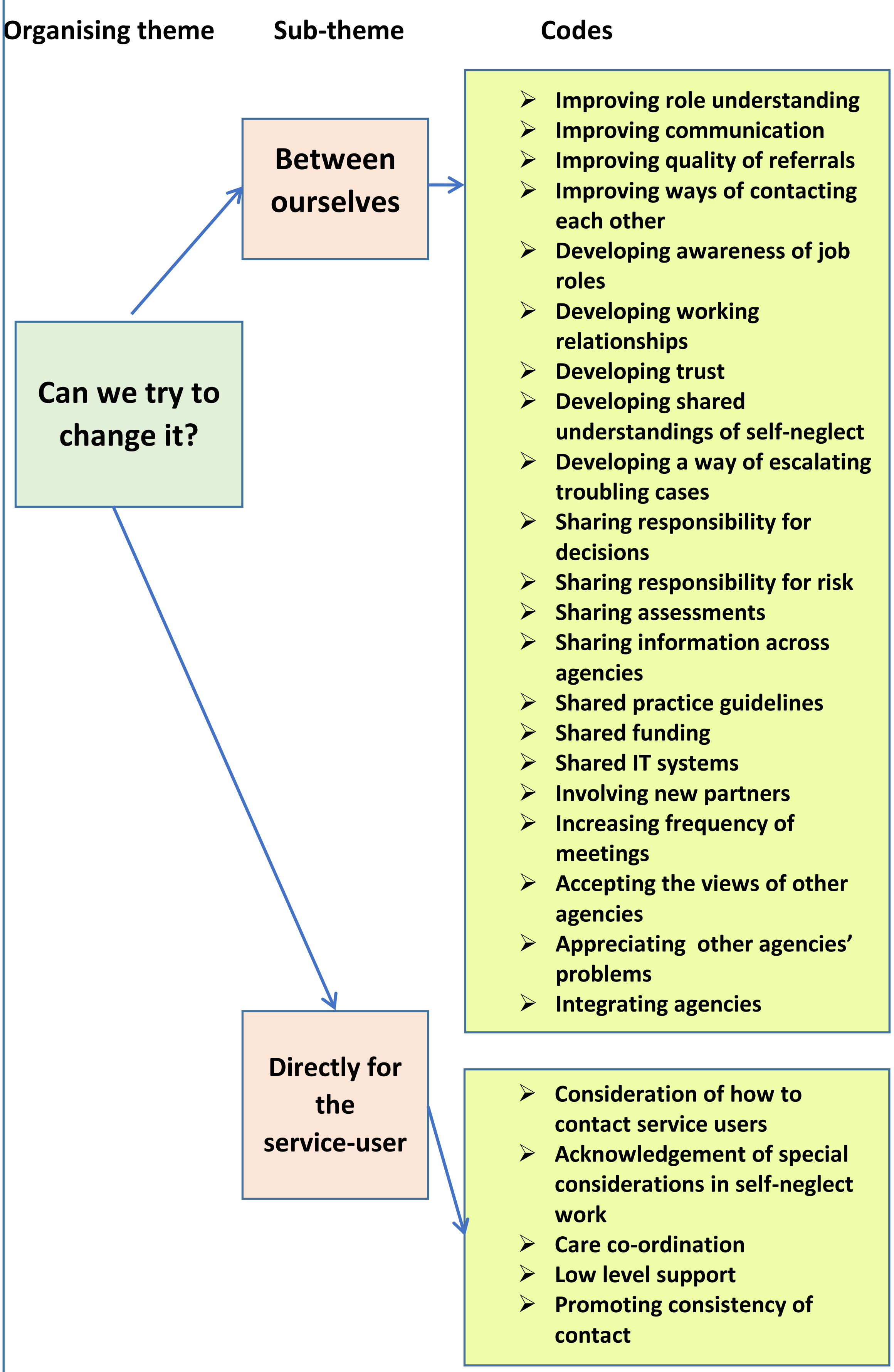


Figure 11: Organising theme 'can we try to change it?' sub-themes and codes

With the wealth of thick data that I collected, I report below on the themes and areas that emerged as most important to the participants and most germane to the next AR cycle. Using the concept of abductive analysis, I have tended to highlight those areas which were surprising and bewildering, and which provide context for the rest of the study. In what follows, quotes are attributed to the particular professional group from which they emanated, but they may be from different interviews, for example, several groups of social workers were interviewed, and the groups are not distinguished in the text. I have used many verbatim comments, to explain and illustrate points, but also, importantly, to enable the voice of the participants to be clearly heard (Corden & Sainsbury, 2006). Respondents are indicated by the initial 'R' and where there is more than one respondent talking, they are numbered. The interviewer, always myself, is indicated by the initial 'I' where this is necessary for clarity.

6.3 Findings from the interview stage

6.3.1 How the participants understood self-neglect

Maxwell (2013) notes that **'**An important, and often neglected, source of theory is the theories held by the participants in your study' (p50). These theories, whether publicly available or privately held, inform what participants do, and thus, Maxwell (2013) argues, we cannot understand their actions without taking account of what motivates their actions, and we may miss important insights borne out of individual experiences. In this section I explore some of the theories espoused by practitioners around what self-neglect is and why people neglect themselves.

6.3.2 The construction of a social problem

In Chapter 2, I suggested that social construction of self-neglect met the conditions necessary for claims-making for a social problem, as described by Best (2013). Participants in this study can be seen to be engaged in the 'social problems work' stage of Natural History Model of the Social Problems Process (Best, 2013) which,

> Involves describing particular people, events and circumstances in ways that fit with the assumptions and claims associated with available social problems categories (Miller & Vitus, 2009, p747)

and whereby they must work on specific cases in the messy real world (Best, 2013).

In terms of a social constructionist perspective on self-neglect (e.g. Lauder, 2001), although this interpretation was not widely expressed, and the 'problem' of self-neglect located clearly with the service user, some participants were edging towards this idea,

> R1: Because she's lived as she lives all her life like that, so, you know, it's not out of the norm for her.
>
> R2: It's a societal construct. (Social Workers)

Many participants discussed why self-neglect appeared to have become an 'issue'. For one participant, self-neglect was contextualised within changes in wider society, whereby,

> people as a whole, unless you have a square house with a driveway and a red car on it, with your lawn done every Sunday, are becoming less tolerant of different people's ways of living (Environmental Health Officer)

Some participants were trying to work out why self-neglect had become a problem. It was seen as something new,

> It's quite like a modern thing isn't it to think of self-neglect, whereas we used to just think 'that's how they want to live, that's their choice' whereas now it's flagged up isn't it? (Community Nurses)

The media were identified as important in shaping the new discourse of self-neglect, both as a serious issue,

> I think it was only about 3 years ago, no so long ago relatively, when it was suddenly recognised, and that was only because of the media, that was because there were programmes on the television, people being evicted, elderly people hunched over, bad landlords kicking them out. But it worked, so it gave a lot of negative press to the landlord, but it worked. (Housing Officer)

And as a source of entertainment,

> R1: And we have all the telly programmes

> R2: Oh, I love all that, obsessive compulsive cleaners (Community Nurses)

Self-neglect had become 'a term whereas it never used to be' (Community Nurse). One participant described how with awareness came new ways of learning to use the language of self-neglect,

> I just think people are a little bit more aware of it and I think people tend to brandish the saying around, you know, oh there's a hoarder or they're neglecting, a little bit more. But, I think that's often because people read things, don't they, and think oh if I use these phrases they're the right ones to use at the time. (Social Worker)

These participants describe how language links to the concept of juridification (Habermas, 1987), that is, an increase in legal regulation and the regulation of new areas,

> R1: I think we've got a lot of legislations now, bandying words about that we never had before, like the deprivation of liberty, haven't we, capacity, safeguarding and-
> R2: Vulnerable -
> R1: Vulnerable adult, self-neglect, yes, there are lots of terminologies out there, aren't there? (Community Nurses)

The 'newness' of self-neglect was also used by some practitioners as a way to advance their own agenda:

> We all employ different strategies and terminologies to get the foot behind the door, and in that one we used self-neglect, we really pushed on that one. That's because it was relatively new in people's minds (Housing Officer)

6.3.3 How participants defined self-neglect

All participants were asked to define what they thought self-neglect was. As was highlighted in Chapter 2, there is no consistent definition of self-neglect in the literature. However, most participants were able to offer a definition of self-neglect which incorporated most of the accepted components (Bates, 2019). One team built up their definition together:

> R1: I think quite commonly people focus on self-neglect as being personal care and clothing and things, don't they, but it's so much more than that ...
> R2: Yeah
> R3: Yeah, I would agree with that
> R1: In terms of medication and you know, like you were saying
> R4: Eating and drinking
> R5: Finances, diet, fluids, household
> R2: Social, leisure

> R1: It's basically every aspect of your life isn't it?
> R3: Yeah
> R2: And you can self-neglect in one area, which will drastically impact on others, then it has a bit of a domino effect I think (Occupational Therapists)

The following, from a team of nurses, incorporates both the physical manifestations of self-neglect, and the idea of acting against one's own best interests, or what other people see as the person's best interests,

> R1: Someone harming themselves. Someone not eating and drinking and washing.
> R2: Changing their clothes.
> R1: Someone who doesn't take always the best, helpful, physical, mental health issue…I was going to say -
> R3: Advice?
> R1: Not advice, I just think they don't always -
> R3: Best interest -
> R1: In their best interest. They don't act in their best interest. Thank you, it was in my head and then it just disappeared out of my head. So, someone that does not always act in their best interest or a health professionals perceived best interest. (Community Nurses)

A more over-arching definition was provided by a GP, who was the only participant to mention self-neglect as resulting from people's difficulties with self-realisation (an area very much neglected by the literature):

> All of the biological, psychological and spiritual needs that would normally be acted upon by the individual, a lack of that. (GP)

Braye et al (2014), following 'a split commonly found in the research literature' (p100), distinguish between cases of failure to care for self and failure to care for surroundings. However, I did not find that participants made this distinction. They were more likely to make a 'split' between the impact of physical or mental health problems on self-neglect,

> Whether it was mental health or whether it was physical health, whether they think they're not unable to or let's say if it's mental health really. I think you can sort of slice it into two I would think. (Community Nurse)

6.3.4 Transgressing normality

For many participants, self-neglecters challenged the idea of what constituted 'normality', in that it represented a different type of normality to that espoused by other members of society, though they acknowledged there was no objective ‘normal’,

> It's living in a way that possibly wouldn't be the way we would live in, whether that be the way someone dresses or chooses to eat or not to eat, it not something that's ... not that anything's every normal, but it's not the norm for say, a health professional. (Fire Officer)

Accepting different norms and standards could be difficult and could cause participants to question their own practice and way of living, and the way other people lived,

> I thought everyone was just, sort of, living like I live, but until you get out there you just think, oh my God, you know, people live like this, but that’s the norm for them. Then you’re trying to, not like be judgemental in any way, but you just try and help them to get a better quality of life and way of living. (Paramedic)

6.3.5 Mental ill-health and depression

As also discussed in Chapter 2, many explanations are given in the literature for why people self-neglect, and this was reflected in the participant’s observations. Frequently self-neglect was seen as having a psychiatric aetiology,

> It’s usually a mental health issue I would say, in terms of an understanding. (Community Nurse)

However, participants were often vague about the particular psychiatric reason for people to self-neglect, and interestingly, the newly introduced Hoarding Disorder (APA, 2013) was not mentioned by any participant. Diogenes syndrome, though never included in the DSM (ibid, 2013), was mentioned by several participants,

> And I said 'it's hoarding' 'What's that supposed to be?' I said 'hoarding is a serious issue', 'well, maybe for Housing, but it's not for us', and I said 'it's Diogenes disease, it's a disease', and it wasn't recognised, wasn't recognised at all. (Housing Officer)

Depression, however, was often mentioned,

> I think we see a distinct link between mental health and self-neglect as well, so depression is something that comes into it.(Advocacy service)

and explanations offered about what impact this might have,

> R1: But I think if you feel lousy in yourself, obviously the home around you is going to reflect on that really isn't it?
>
> R2: And that's what we see in most houses (Domiciliary Care Workers)

Sometimes this could be extreme, and left the worker with existential dilemmas,

> I've worked with people who genuinely don't care about their wellbeing because they don't want to be here anymore. You know, they're knackered with life, they're not dying as quickly as they want to. (Social Worker)

Loss and bereavement were mentioned as reasons for both neglect of the self and neglect of surroundings. In this example, the participants attempt to articulate an explicit theoretical approach to understanding what 'triggers' the problem,

> R1: A lot of the hoarders I've been to, it's normally been triggered by bereavement
> R2: Yes, I was just going to say that
> R3: It's an attachment thing
> R2: I was going to say that, either bereavement or abuse (Fire Services)

However, others mentioned the 'gradual slide' into self-neglect, not necessarily involving triggers, where people have been maybe teetering on the edge of coping for quite a long time (Paramedic), but which is only noticed by others,

> You can slip into that pattern can't you, without knowing that you're not doing or maintaining some of the things which, standards generally, that other people may notice and pick up on. (Social Worker)

Thus it was not the self-neglecting person's fault that their standards weren't being maintained, but the fact that they simply couldn't maintain them,

> I think it can be that people let things build up, they don't see it happening. You don't in your own house, you don't, if you went back and probably had a look at the decorating, you know, once you've decorated you're horrified aren't you, and you start seeing it elsewhere, nobody's noticed it happened because it's been so insidious over time. (Occupational Therapist)

Alcohol and substance misuse were also mentioned as contributory factors:

> R1: It's the drug users, the alcoholics, the chaotic families, what is self-neglect? If you're an alcoholic ..
> R2: You don't eat
> R3: You may not hoard, you may not have anything, all you think of is the cider in The fridge. (Police)

Participants talked about the shame that self-neglecters experienced, and, in this case, how they might respond to it:

> R1: She was saying 'I'm embarrassed, I know what I've done and I can't help it, and we were saying ' yeah well, we understand that that's happened, let us help you, but

> she was like 'no'.
> R2: Maybe she's just too embarrassed. I think sometimes it gets that big a thing for them that it's like, no ..
> R3: But that's even more upsetting isn't it, because it's just going to build and ..
> (Fire Services)

6.3.7 Self-neglect as a 'choice'

Many practitioners spoke of self-neglect as a choice, particularly a 'lifestyle choice', but many clearly struggled with this notion,

> I've had it where they've said it's a lifestyle choice, it's lifestyle choice and that's all I've had.
> (Housing Officer)

Others discussed the issue of meaningful choice,

> R1: She hasn't really got a choice has she? Because she's there. She's not going to move anywhere else is she?
> R2: I suppose she's been given choices, but does she understand those choices, and she still sticks to the same thing doesn't she, 'leave it as it is'. (Community Nurses)

Others espoused the rhetoric of choice, but admitted that it was hard to accept,

> Some people self-neglect and they have got capacity and they choose to live the way they live, it might not be for everybody's standard, and we all have different ways that we function don't we, so that's the hardest part, in terms of from a professional point of view.' (Community Nurse)

Some refuted the idea of choice completely, incidentally, showing an extraordinary degree of empathetic engagement,

> Imagine a fog, and it's so foggy you can't even see your hand in front of your face, so how can you make a decision and a lifestyle choice, because you don't know which direction you're going in, you don't know who's there around you, you're just totally absorbed in this really thick, like walking in treacle in a pair of wellies, and I don't think that's a lifestyle choice. (Homelessness Services)

For some, the argument that the self-neglecting person had chosen this path was hard to comprehend, in that accepting self-neglect as a lifestyle choice seemed to run counter to their own ideas of duty of care. They struggled to reconcile autonomy with beneficence (Beauchamp & Childress, 2013),

> And she thinks she's living quite normally and because…she's got capacity to make that choice who am I, and what am I doing going in to tell her to live in a different way? It makes me feel uncomfortable. (Domiciliary Care Worker)

There was, however, a sense that it was very hard to challenge the mantra of choice,

> And also, right, this will sound...are we still taping it? Sound really mad but in my world it might sort of look like we give a lot of credence to people making choices, but sometimes I look and I think, you know, if you really physically are not able to manage…(Community Nurse)

To challenge the principle of choice was 'really mad', an extreme action. One participant described how she had defied instructions to allow choice (in the form of a care plan), but offered justification for doing so,

> If I hadn't of (sic) put that toast in front of that lady, if I'd stuck to the care plan, it would have ended up in neglect because she kept saying every meal time 'no'. So you're saying well we're giving her a choice and not giving her anything, but we just stopped a neglect case there. (Domiciliary care worker)

The invocation of the 'lifestyle choice' argument by some agencies (notably social services) was seen by others as a reason simply not to intervene,

> R1: Adult social services is a lot different to children's social services. My experience with them is that they don't do much.
> R2: They say it's a life choice and therefore they can't do much about it. (Police)

6.3.8 Unwillingness to change

Although it could be argued that some of the motivations mentioned above were offered in mitigation of self-neglecting behaviours, there was also much discussion in the interviews of self-neglecters who were unwilling to change in the way that services required of them,

> If people don't want to change, then they don't (CMHN).

This may not be of itself surprising, because these may be the service users who are frustrating the best efforts of participants on a daily basis, but some of the reasons for their perceived unwillingness were interesting and under explored in the literature. Self-neglecters, particularly hoarders were described as 'ingenious', 'very, very savvy', 'very clever', in how they found their own solutions, or thwarted the intentions of professionals. To deal with them, ‘you’ve got to be one step ahead’. (Housing Officer)

Keeping ahead was important, because service users might otherwise use strategies to placate professionals,

> To make me happy, he says, ‘look what I’ve brought’ and he’d brought a Hoover (Housing)

or manipulate them,

> Now, what we’ve sorted twigged is, it’s very clever the way he’s done it. He’s all, ‘yes, yes, come round and you can help us clear it.’ So, we’ll go round for three hours and cart stuff down three flights of stairs, fill our cars, stand and wait at the tip, but he’s not actually doing a thing. (Housing)

Not really mentioned in the literature, but a more pragmatic explanation by participants for extreme acquisition, was simply the usefulness of stuff to the person and their plans for it,

> ‘it just gets where they get fifty things, fifty broken things, that together, collectively will work as one, but they just never get round to it’. (Fire Services)

This accords with Löfgren’s (2017) argument that those who live in *creative* disorder are given greater leeway by others. Several participants felt this was due to older people who hoarded ‘coming from that sort of era, it wasn't a disposable society.’ (Social Worker), and older self-neglecters not wanting to ask for help,

> I don't know whether we'll have that problem in the future, as generations change, because there's quite a sea-change that you see with younger people they're more like, you know, "what can I have, what can I get?" It's quite different to this, like, 80-odd year olds that we're seeing now. They are…brave. (Community Nurse)

6.3.9 Fear of services and refusal to pay

Fear of services, identified in the literature, (e.g. Braye et al, 2011; Lauder et al, 2005b) was mentioned by some groups, particularly social workers, who saw themselves as ‘a very intrusive department’ with a stigma surrounding their involvement, which meant that,

> ‘In fact a lot of people DON’T want us involved, they'd rather have anybody else but us involved.’ (Social Worker).

However, more frequently mentioned was the belief that many self-neglecting people, particularly older people, refused services (usually social support services) because they did not want to pay for them,

> I hate to be the voices of doom but I think, you know, talking about what you were saying about you work long and hard with a person, you do the home visit, you lay the groundwork out about making changes and then you have to drop the bombshell, you know, we can support that change, but there's going to be a cost, and often that's the stumbling block with our, with our patients, that they don't want to incur those costs. (Occupational therapist)

Some social workers felt their job was made harder by other services not telling service users that things like respite services were chargeable, leaving it for the social worker to do so. However, they were clear that if a service was desperately needed, they would ‘fight the money second, you get the support in first.’ (Social Worker)

Thus, many explanations were offered for why people might neglect themselves and their environment. However, sometimes, there was simply no explanation:

> There are still these grey areas that aren't catered for under any policy. The weirdness of behaviour comes into it sometimes and it's not covered. (Housing Officer)

6.3.10 Positioning oneself in relation to self-neglect

The participants, working in an area which can be so challenging and inexplicable, talked about self-neglect in ways that help them explore their own ideas and values. Self-neglect is an area that ‘we can all identify with a bit of it anyway’ (Social worker) and participants frequently explored whether as professionals, they were ‘at risk’ of neglecting their own environment, at home or work,

> R1: Like you said before, isn’t it, standards in some homes, you know, we go home and some standards in our kitchen sometimes [Laughter]
> R2: Just come in here sometimes, yes. (Community Nurses)
>
> so therefore am I hoarding, you know? My garage is chocka when I open it, am I hoarding? Would I say I’m hoarding? (Advocate)

One nurse spoke of how ‘you start neglecting yourself to a degree’ because she had no time to eat her lunch or go to the toilet.

Participants often used themselves and their families as comparators,

> I always think that if I go into someone’s house would I leave my family member like this? That’s just the way I think. We all do things that we shouldn’t do like making cups of tea or…I won’t see someone without milk, do you know what I mean, kind of thing. (Housing Officer)

In one team discussion it was emphasised how important this perspective was,

> I think that's a really, I think it's a really valuable benchmark, because it's a way of empathising, isn't it? It's a way of trying to understand. It's not necessarily a way of putting your judgement on things, or your standards on things. (Occupational Therapist)

The issue of not ‘putting your judgement on things’ was one that exercised many participants, who had to accept that in some situations there was nothing they could do, for whatever reason, but found it extraordinarily hard to do this, ‘finding that professional balance and having that inner, really, fight with yourself’ (Social Worker). The difficulty of being in a situation where,

> you're there and you're thinking 'I can't believe I'm having to let you go back into that situation, but you have a right to do that’. (Consultant)

forces participants to think about, and question, their own values,

> you have to consider, you have to consider you own traits, your own view really, your own personal ... you've got to look at them and their life and where they've come in their journey to find a little even ground of acceptance for it. (Occupational Therapist)

In this sense, it is a unique area of work,

> self-neglecting behaviours it’s a grey area because it’s a judgement. It’s not like physical abuse or something like that. It’s very much down to your values and what you consider to be acceptable, so it can be very, very difficult. (Housing Officer)

Thus, practitioners individually have many different understandings of what self-neglect is and why people self-neglect. By its very nature, work with self-neglecters is difficult, worrying, frustrating, demanding.

The dedication and commitment of all of the public servants whom I interviewed shone through the interviews. Participants talked about how much satisfaction they derived from working with highly vulnerable people, how important it was to build up trusting relationships and work slowly with people who self-neglected, taking ‘baby steps’ (Environmental Health Officer) or ‘pigeon steps’, (Community Nurse), a ‘hand holding exercise’ (Environmental Health Officer). They described not wanting to offend service users, by wearing protective clothing for example,

> R1: See, you've sort of got to go and not try and insult the patient at the same time, saying 'we're coming in ..
>
> R2: The trouble is, you can go into that patient, identify that you need that equipment, then you have to come back and order that equipment, and in the meantime, in the fortnight it takes to get here, you're having to still go in.
>
> R1: And maybe they'll say 'why are you wearing this, I think I'm clean', you feel like you're insulting them then.
>
> R2: Offending them, yes. (Community Nurses)

Fundamentally, all the participants wanted to make things better for the service user, to help them to improve their lives in some way,

> and you've got to feel in your heart of hearts you've done everything haven't you? (Community Nurse)

That was what they were there for. However, in many cases they were not able to do that. As individuals, they were left feeling frustrated and in many cases, feeling guilty that they had not been able to effect change,

> it goes to a personal thing then doesn't it that you feel worried, you feel guilty that someone hasn't got any food. (Community Nurse)

All of these individual feelings were carried into their working within their own teams, and into the multi-agency arena, where they were likely to be compounded and exacerbated.

6.4 Multi-agency working with people who self-neglect

The deductive aspect of my data analysis for the themes relating to multi-agency working, correlates well with broad themes identified in the research literature, albeit applied here to working with people who self-neglect. Issues such as lack of knowledge of the professional role of others (e.g. MacDonald et al, 2010; Stevens, 2013; Ambrose-Miller & Ashcroft, 2016; Sprung & Harness, 2017; Beaulieu et al, 2017), or poor information sharing (e.g. Stevens, 2013; Machura, 2014; Cameron et al, 2014a; Jolanki et al, 2017; Beaulieu et al, 2017; Waring et al, 2018) were identified by participants. As previously discussed, many of these themes mapped directly on to suggestions for change, in response to the question, 'What do you think could be changed in the way professionals work together to improve support people who self-neglect?' These ideas became some of the specific issues examined in the subsequent AR cycles. However, there were other issues raised which were specific to working with self-neglect particularly, or within the safeguarding arena in general, which were less well identified in the literature, and which also became issues examined in subsequent cycles as being amenable to change. These were suggestions such as having a low-level support service for people who self-neglected, or having way of escalating very complex and high risk cases.

From a more inductive perspective though, I began to realise that there were issues which were being raised and discussed by participants, in relation to their experience of multi-agency working, which were not present in the literature, and not mentioned in their 'Headlines' as ways in which multi-agency working could be changed. There were also the issues which from an abductive perspective 'surprised' me. These offered more nuanced understandings of the multi-agency working picture in relation to self-neglect, which, I realised, could potentially hinder any efforts to change how things were being done.

6.4.1 Structural problems

There were many factors which participants mentioned in relation to their work which were deeply problematic for them. Working with self-neglecters seemed often to bring these areas into sharp focus. Working with self-neglecters is time consuming and demanding, and often, as the previous section showed, will result in an impasse or a failure to be able to help.

Participants spoke of the sheer volume and complexity of work which they faced, and the shortage of time in which to do it. This was particularly acute for the community nursing teams in the study,

> But I feel like we're just sort of drowning, it's how it feels out here we're drowning in the level of complexity that they're expecting us to manage out here. And we're drowning, just with the volume of work and record keeping and everything. So it just feels sad, really, in a way. (Community Nurse)

Management demands made it feel 'like a constant police state', where it simply was not possible to 'keep all these people safe' (Community Nurse), and where,

> In the end it becomes, it's not actually achieving what we want, because we're spreading ourselves so thin. We're doing too much. (Fire Services)

Many participants spoke of the impact of budget cuts on their own agency,

> We're expected to produce this deluxe service in the community with third world funding (Community Nurse)

and on other agencies,

> With their cutbacks nine times out of ten it now falls to us. (Paramedics)

They spoke of how that meant services disappearing,

> Everybody's getting stripped right back because of funding. So, those layers that were there to pick these people up aren't there anymore. (Housing Officer)

of changes of personnel in other agencies and their own job uncertainty. It had 'gone beyond trimming the fat' (Fire Services). This led to demoralisation and disempowerment for themselves, and anger about the impact upon the people they were working with,

> What about that social inclusion? That’s part of neglect, you know what I mean. They’re sitting there on their own all day. You want me to run in, bung them a meal and run out. That’s not care. (Domiciliary Care Worker)

6.4.2 Fear of getting into trouble

As I became more immersed in my data, I began to realise that many participants were talking about the individual fear that they experienced as part of their work, and how this might be exacerbated by working with people who self-neglected, where a risky situation could not be easily resolved. Participants had not been explicitly asked about their fears, but many conversations came round to this,

> R1: People are frightened of… it's the legal aspects I think, that have taken precedent over common sense, sadly.
> R2: I think everyone can say we’re worried…I think we all are. (Housing Officers)

Fears took several different forms and some were less clear than others. Frequently expressed was the fear of ‘having the finger pointed at you’ (Housing Officer), of having your practice scrutinised if things go wrong, and always having to be alert lest something should come along and ‘bite you on the bum’ (Paramedic),

> It's like, 'oh God, if I do this, if I make a mistake on this one, then the shit will hit the fan. (Community Nurse)

Individual accountability was often discussed,

> Knowing also that if it all goes wrong that we'll find ourselves under the microscope. Why didn't you do this, why didn't you do that, justify that you took appropriate action. (Housing Officer)

There was the fear of being ‘reported’ for not doing your job properly, identified here as a new phenomenon,

> And, you know, the place is a minefield these days for people reporting everyone, it's like a suing nightmare nowadays, compared to how it used to be. (Community Nurse)

Being named and shamed in the media was a fear often expressed, partly because of the one-sidedness of this kind of situation, where actual events could be easily distorted,

> Yes, because of the situation and the press involvement and everything because they were just saying ‘heartless landlord kicks out old age pensioner.’ That wasn’t the case. We’d tried everything. (Housing Officer)

The threat of invoking media attention was mentioned as a way of threatening other agencies to take action:

> R1: And it's ... you know, we go out on these cases and, you know, people will mention "this is going to end up in the newspaper", you know, it's that type of ..
> R2: A scare tactic, all the time. To get us involved. (Social workers)

Many participants discussed the fear of loss of professional registration, whether something going wrong would affect ‘my nurse PIN’, ‘GMC registration’, ‘being HCPC registered’ (the latter applicable to social workers, occupational therapists and paramedics). It was interesting that belonging to a professional body was seen mainly in punitive terms rather than being an empowering development in their careers.

People expressed fear of being part of a Safeguarding Adults Review, and vividly imagined their interlocutor when describing what this might be like,

> In Safeguarding Adult Reviews, it will be asked ‘what did you try, what did you do, what was effective, what wasn't effective, what worked, what didn't work’. (Social Worker)

For one participant, this fear had distorted organisational responses to the extent that,

> Organisations are mindful of being named in a serious case review, so what their activity is, is make it try to look as if they’ve done enough without really doing enough. (Housing Officer)

However, there were many fears on an even more serious level, the fear of ‘all the litigation’, ‘because we live in such a litigated society’ (Community nurse), and fear of the court process. One participant believed that ‘they will tear you to bits in a court of law’ in relation to self-neglect cases, and another described how colleagues had effectively threatened her with their fears,

> I've heard it said to me, from health professionals, in regards to a particular case where the person was self-neglecting, 'well, the coroners would have a great time' if something were to go wrong, (Social Worker)

Associated with this was the fear of being convicted of a crime,

> Assault, it’s criminal charges, isn’t it, if you get done for assault for… if… (Paramedics)

Several groups expressed fear of the consequence of this,

> R1: If anything goes wrong, that's our job, that's our lives, that's our mortgages and our families, things like that.
> R2: And our conscience (Police)

Several of these fears were discussed together by one group, including the poorly defined ‘litigation thing’ mentioned above,

> R1: We live in a world of ‘what if’, don’t we? HPCP is always there, you know…
> R2: It’s the litigation thing hanging over you.
> R3: The mortgage is gone. You’re out on the streets.
> R2: Yes.
> R1: There’s always that fear factor, which is not nice, but you know it’s part of the job that you take on. (Paramedics)

There was acknowledgement of what these fears meant in practice,

> I think there's an awful lot of pressure on us, whether it's true or not, because of blame and compensation and court hearings and all that sort of legality of it, that the reality of the situation is often ... fuzzy. (Fire Services)

Ultimately, the overarching fear is expressed by this group of nurses in the context of the pressures on them,

> It's just at the moment, we're flying a plane, trying to keep it level, whilst everything inside is all turbulent, trying to get it all together but trying to keep everything steady, without, at the end of the day, which is our worst fear, is killing someone (Community Nurse)

6.4.3 Ways to live with the fear: Cover your back

The picture that emerges is one of a workforce fearful on many different levels that something will go wrong in their work with self-neglecters, which will rebound on to them. People described what they did to mitigate this. Firstly, practitioners concentrated on ‘covering their backs’, as a way to avoid negative repercussions, even though they were sometimes ashamed to admit that this might be their motive,

> I’ll be honest, this might sound really bad, but a lot of the stuff, I don’t want to say that I do, it’s not the reason why I do it, but it’s also where you need to cover your own back as well. ‘(Housing Officer)

Other people were quite open about the extent of their defensive back covering. One participant was asked by another whether she had received any training in the Mental Capacity Act. She replied,

> No, not really, just the signs for what to look out for and what to do to cover our backs when dealing with somebody.

There was discussion of the charade of behaving in this way, despite its perceived necessity,

> It can sometimes feel farcical that you're going through the motions only to, dare I say, cover you own back. But you've got to, haven't you, you've got to cover your backside. (Housing)

Some groups, particularly community nurses, saw the act of covering themselves as incompatible with good patient care, and were saddened by this,

> My covering myself is taking over from the decision of looking for the best interests of the patient, and that's completely a terrible thing to be saying, (Community nurse)

6.4.5 How to cover your back: Excessive documentation

Extensive and somewhat unnecessary documenting of situations was seen as an important ‘back covering’ technique,

> It's also important for us to make sure, when you have had that conversation that, again, it's documented on our system to show our response as well, to see what they've said but also if they ever come back, it's there, documented. (Social worker)

However, it was not just the documenting that was important, but documenting in the ‘right way’ (Community Nurse) to cover yourself. This might lead to ridiculous extremes,

> Just trying to get them to write in that right way to cover themselves because the writing it's just ... you know, like, it's like War and Peace every day. (Community Nurse)

6.4.6 How to cover your back: Passing the buck

A key strategy for covering one’s back, in relation to self-neglect cases, was to pass them on to other agencies. Participants discussed this from two perspectives, how they felt when other agencies ‘passed the buck’ to them, and how they dealt with intractable problems by ‘passing the buck’ themselves.

Feelings of indignation and anger were expressed by most groups of participants towards other agencies who were perceived as passing the buck, summed up comprehensively here,

> R1: From what we do it’s nothing to do with it being an emergency, it’s just Everything gets dumped on ..
>
> R2: Yes, everyone’s covering their own back, the other services, they need to send somebody. They’ve tried sending the GP, the GP can’t go or has left for the day. They’ve tried sending the CPN, but the CPN can’t go for X, Y or Z reason. Crisis team involved, but there’s thoughts they might have had alcohol so they can’t get round. We need to send someone. Send the ambulance. We’ll send the ambulance. (Paramedics)

Some participants felt that this was done quite openly,

> See, sometimes you do get really good people to work with, and then other times you ... you ... it's quite blatant that they're quick to pass the buck. (Fire services)

Other agencies were described as ‘negating their responsibilities’ (by Social workers), and entering into a ‘blame game’ (by Housing). Passing the buck was also described as a negative circular process, whereby what is passed on is then passed back,

> A lot of this as well is about, well we’re doing our bit and we’re passing it on to you now. Yes, well we’re passing it back to you, and so on and so forth. It’s during that period that things escalate, they get worse and that’s why then we do another referral, that’s knocked back and we do another referral, that’s knocked back and then finally they’ll accept it and say, ‘why have you waited this long? (Housing Officer)

Some practitioners felt that they were taken advantage of by other agencies because they could not refuse to take referrals as others did, a feeling that was particularly acute with people who self-neglected,

> We are the dumping ground as well. (Community Nurses)

Or that they were the only ones acting generously,

> It’s like 'well, who's going to do it?' so you just go and do it.(Environmental Health Officer)

Practicing defensively by passing cases on, and identifying you own agency as doing the buck passing, was, unsurprisingly, much less frequently mentioned,

> If you want, some kind of thing you need to pass in on to them, to cover our own backs really as well. (Domiciliary Care Worker)

Where it was confessed to, this was often in a way which exonerated the participants involved, as in this case, where the belief that something isn't 'quite right' permits passing it on,

> It's relatively easy for us, in terms of, we go there and 'this isn't quite right' so we put the referral in, to say why we don't think it's quite right. And it's usually left to another agency then, in that grey area at the end of the spectrum, to make that decision. (Police)

6.5 Role Understanding

6.5.1 'They don't understand our role'

Role understanding in multi-agency working is identified in the literature as a key factor that can lead to better patient outcomes (e.g. Suter et al, 2009). In this study, the belief that other agencies simply did not understand the role of the participant's own agency, whether through ignorance or a refusal to learn, or even 'tradition', often compounded the feeling of being 'dumped on'

> That's where the total lack of understanding comes in to play about the respective roles. (Housing Officer)

In practical terms, this could mean unfairly being foisted with the job of others,

> You're constantly putting your Columbo coat on, and spending ages investigating what's gone wrong, and who's the care agency, and finding out what's going on, whether it's self-funded, whether they're funded, and it's just this ridiculous. (Community Nurse)

The lack of role understanding was felt to be impeding multi-agency working,

> I mean, when we try to move through into integration it's been very, very difficult. There seems to be a real stubbornness in trying to understand what we do because it is complex and it is so varied (Social Worker)

However, some participants extended this idea of wilful misunderstanding, to suggest that not only did other agencies understand their role, they exploited it,

> R1: I think that's why they do it though. I think they understand our role very well and they exploit it because they know we have a duty of care to do something. That's why we get a phone call from social services on a Friday evening or just before they go home..
> R2: Yes, time and time and time again.

R3: I think they understand it very well and they exploit it to essentially make us come and do their job. [Muttering and quiet laughter] (Police)

6.5.2 Professional ‘preciousness’

Several groups identified a feeling of snobbery or preciousness from other agencies towards their group’s role, they were ‘just the thickos’ (Housing) and it was interesting that this applied across agencies,

R1: Or it’s like, I know better because I’m a nurse and I’ve got so many qualifications, you’re just a social worker.
R2: Yes, you’re just a social worker.
R3: Some do have that attitude, don’t they? (Social Workers)

This contributed to the feeling that multi-agency working could not be done on an equal footing,

> I know there's a lot to talk about in, sort of, partnership working but there is still ...some of the professions, and social care is one in them in particular, where they'll say "we know our thing and we'll ask you for everything you know and we'll tell you what we think you ought to know". So it's not you're a relationship of equals, they don't view it in that way. (Housing Officer)

Attempts to remedy it were not very highly thought of,

> We have been invited to afternoon tea with the district nurses, but then at the bottom it says please bring some food [laughter]. (Social Workers)

6.6 The development of conflict

There are therefore, some powerful forces at work in multi-agency working revealed here. As will be discussed in chapter 8, some of these reflect themes found in the literature. Practitioners are uncertain in their individual practice, which cause them to be fearful. Fearfulness results in self-protective strategies, such as ‘covering your back’. When this fails, or as part of this, difficult cases may be passed on to others to deal with (‘passing the buck)’. The next section highlights how problems with multi-agency working are compounded by issues particularly associated with self-neglect, which as has already been discussed, presents many ethical and moral dilemmas for practitioners.

6.6.1 Differing personal standards of hygiene

The concept of different agencies having different standards in relation to self-neglecters was one which was widely discussed,

> I think we do have different standards and different things that we look at. I think where he was coming from was I know they're eating, they don't look particularly dishevelled, they're not particularly smelly, so he was taking a different view of it to us. (Housing Officer, talking about a Social Worker)

There was almost a sense of pride in not being shocked, that this indicated greater professionalism in some way,

> They were very shocked at the state of the house and couldn't believe somebody was living in these conditions, and I was very much like 'well, I see it literally every day with my service users, and I wouldn't necessarily class that as self-neglect'. (Community Mental Health Nurse)

Other agencies were seen as unrealistic, naïve and over-exaggerating,

> To me I think her property is liveable from what it was, whereas like someone, like, these nurses going in and they come out and they're huffing and puffing on the phone, you know, you can't get to her chair because of this. You're thinking, well you couldn't get to her a few weeks ago. (Housing Officer)

Groups of participants predominantly presented themselves as more permissive and tolerant than their colleagues in other agencies,

> And we do find it quite funny, because I went in one recently and it was 'I've had 20 years' experience, and it was the worst house I've ever seen', and you walk in and you think ok, my house is worse' [everyone laughs].(Environmental Health Officer)

Only rarely did participants reflect on how other agencies viewed their attitudes,

> I think sometimes they see us as being a bit dramatic over things as well, you know, when we might say 'well, this person isn't safe to be left here and whatever, and I think that, specially the GP's sometimes, see you as being a tad dramatic, 'oh, it's just the dramatic district nurse', you know. (Community Nurse)

6.6.2 Differing ideas about risk in self-neglect cases

Compared to other areas of adult safeguarding, such as physical abuse where it would tend to be agreed by practitioners that physically abusing a vulnerable adult is always wrong, consensus around self-neglect is far more difficult to achieve. This is demonstrated around the area of risk, in relation both to risks posed to the self-neglecting person by hazards in their home, such as the risk of fire due to hoarding newspapers, and risks associated with neglect of the person, such as malnutrition. Similarly to the points above about standards, risk is perceived very differently by different groups, with each group believing that they are right and others wrong,

> I do think other services don't have that balance of what's acceptable for that person and what's actually passed the line where the risk is high. (Social Worker)

Some participants tried to find explanations for this,

> It's a different bar, different thresholds as well though. It's like what we might count as disgusting, or the legislation would apply or whatever, wouldn't be exactly the same for different teams, different markers they've got to meet. (Environmental Health Officer)

The risk aversity of other professionals was explicitly criticised:

> R1: I think we've gotten into a culture where, especially with our health colleagues, it's they want to wrap people up in bubble wrap and it's gotten to that point where we're not allowing people to make those decisions.
> R2: People are risk adverse, aren't they?
> R1: Yes, that's the word I was looking for. That's the danger that we're getting into, so… (Social Workers)
>
> R1: I often find health are quicker at wanting people in care.
> R: They're more risk adverse, aren't they, I think?
> R: Yes.
> R: Than social services. (Advocates)

6.7 Using the Mental Capacity Act 2005 in multi-agency practice

Perhaps the main surprise from analysing the data from an abductive perspective was the extent to which all of the previously identified issues in relation to self-neglect and multi-agency working coalesced around applying of the Mental Capacity Act 2005 (MCA) in work with people who self-neglect. Some of the issues raised by participants are present in the literature, but other significant ones raised in this study do not appear in the literature around the MCA. These will be explored further below.

It was clear that mental capacity is a crucial area of consideration for practitioners across the board,

> I: What's the significance of whether someone who self-neglects has capacity?
> R: Well, it's the sun and the moon really. (Occupational Therapist)

> There's like a little fine line, and it's all about capacity. (Community Nurse)

Despite the fact that the MCA came into force 13 years ago, it was described as ‘a massive problem for workers.’ (CMHN), ‘hard to understand’ (Community Nurses) ‘blurred’ (Psychologist) and difficult for all agencies to operationalise,

> And it's not just a problem for us, it's across the board, mental capacity's a problem everywhere, nobody seems to be able to decide on it (Fire Services)

6.7.1 The Mental Capacity Act 2005 as a source of fear

Despite the MCA being designed to simplify the process of understanding whether a person could make decisions for themselves, operationalising the MCA with people who self-neglected was presented as a source of difficulty for many practitioners, which added to the fears previously discussed in this chapter,

> So capacity, it's a really, really tricky one to get right. (Occupational Therapist)

The process of assessing capacity was viewed by many participants as complex and worrying:

> And if we discussed every single thing with people all the time to check they had capacity, given the type of people we're dealing with, where a lot of them have got potential issues with capacity, it's a bit scary, you know, like, how can you constantly show that you've checked on that? (Community Nurses)

Participants were fearful of making mistakes, and being blamed,

> Something goes wrong, or it's misdiagnosed, or they have got capacity and you say they haven't, who is it who's going to get blamed for it? (Fire Services)

One participant described vividly how fear about assessing capacity manifested itself, and related it directly to fear of being professionally penalised,

> A position where I’d like to get people to in the team, so that the word 'capacity assessment’ doesn't send people into this place of anxiety, and you know, the hairs are standing up on the back of the head, when everybody starts looking at their piece of paper and thinking 'no eye contact, no eye contact, they mentioned capacity'. I’d like to get to a point where somebody feels comfortable asking questions and doesn't feel that they are going to be taken down a disciplinary route for having said something or having an opinion. (Psychologist)

6.7.2 Not understanding the Mental Capacity Act 2005

Lack of understanding of the MCA in relation to self-neglect was clearly apparent and had various dimensions. There were participants who confessed to finding the MCA confusing and difficult,

> It makes me dizzy speaking about it. (Community Nurse)

Others felt that it meant that real problems were missed, and 'common sense' overruled because practitioners focussed solely on capacity,

> I think it's just that legal side of it that's just become, I feel, a bit top-heavy, and we're missing the point of 'actually, we've got a patient here that's not eating and drinking, or not washing, going out', and it gets missed because we're banging on about capacity. (CMHN)

The binary nature of MCA decisions was also difficult,

> Because capacity is so hard to understand as well because you think somebody with capacity they've either got something or they haven't, but it's not that simple .. (Occupational Therapist)

Others found the assessment of capacity a rather mysterious process and were not sure how it was done, even though they were working with it every day,

> R1: I thought they had to go to hospital to get it.
> R: No, I think somebody just comes out and has a chat with them.
> R: Yes, my client has never been to the hospital, so I know for a fact they don't go into hospital. (Housing Officers)

Several groups inadvertently expressed misunderstanding of the MCA in the course of their discussions. Others incorrectly elided the MCA and the Mental Health Act. This served to confirm the views of those agencies who identified a lack of understanding of the MCA by other agencies, and 'different ways of defining capacity from different organisations' (Social Worker)

Some participants were uncertain whether 'universal' capacity was being assessed (the ability to make your own decisions about everything), rather than decision specific capacity (the MCA is clear that it is the latter):

> R1: The nurse has taken it back and she's going to see the doctor and ask whether he can do it, and it will just be about the accommodation, not about everything, whereas the district nurse was under the impression that capacity means everything, that you can't make any decision.

> R2: It does, you have to have capacity on every single thing don't you? So you might have capacity over accommodation...
> R3: I don't know, there's different domains, isn't there?..
> R2: But you could not have capacity at washing or dressing..
> R2: Well, this is it ..
> R1: You've got to assess per issue, it's not just one size fits all..
> R3: Yes, that's right, it's not generic, it's per domain I guess isn't it?
> (Occupational Therapists)

Another participant, a community nurse, understood capacity as ‘a moveable feast, depends what you're asking them’. This kind of misunderstanding was a great source of irritation for other agencies. However, agencies often seemed to believe ‘everyone else’ did not assess in a decision specific way, but that they always did,

> That is a massive hurdle for us to cross. Even if we can get them to admit they lack capacity, well they lack capacity in what area and when? Capacity is now case specific. (Housing)

Many participants discussed their feelings about capacity assessments done by others, often from the perspective of absolute disbelief that the self-neglecting person had been assessed to have capacity,

> R1: Because the house was filthy...
> R2: Like it's given her bad dreams...
> R3: Faeces all over the floor...
> R1: And you're thinking 'how on earth has this woman got capacity?’ (Fire Services)

This disbelief often led to disagreement about each other’s assessments,

> You find as well people who clearly haven’t got capacity they’ll say they have. (Housing)

Some practitioners were irritated at not being able to carry out assessments or contribute to assessments when they were the person who knew the service user best,

> From my experience when they conducted we're not even in the room. We're not asked about anything, so yes we might have important information but they forget to ask us. It's frustrating. (Housing)

Conversely, other participants were frustrated by being asked to carry out assessments when they didn’t know the person at all,

> We're going in as a one-off to do a capacity assessment, it's wrong it should be someone who knows that person better. (Social Worker)

They were also annoyed by other people pre-judging or giving an opinion not based on evidence,

> I'd say every single case I've had, that has had some one that self-neglects, ‘they haven't got capacity’, in regards to some professionals' opinions. It's every case, not just occasionally, I think I've had that conversation with various people on all cases that I've had that have had self-neglect. (Social Worker)

6.7.3 Who should carry out the assessment?

An elaborate picture emerged of which agencies did and did not carry out capacity assessments. However, these decisions often appeared to have been arrived at informally, by tacit agreement, often within the particular team or service. In the MCA and its accompanying guidance, no agency is excluded from this responsibility. They also do not have to be done by one person alone. In the community, social workers tend to carry out the majority of assessments and one participant felt this was because ‘no other agency particularly wants to do capacity assessments’. Reasons given for not wanting to do them included not being paid enough, not having the training, and not having sufficient expertise or qualifications. However, the issue of who does them was a source of irritation for practitioners. Many groups were frustrated that CMHN’s did not carry out capacity assessments. It was reported that Community Nurses didn’t feel it was ‘appropriate for them to do it’ (Social Worker). The police and fire services were clear that they did not carry out assessments. However, paramedics did carry out MCA assessments, and were often called on by the police to make capacity decisions. It is very hard to see the reason for this, but it left the paramedics feeling very exposed:

> I personally feel we’re quite vulnerable assessing capacity as paramedics we’re not social workers, we’re not doctors, to assess someone’s capacity I think is quite a big thing to do. (Paramedic)

6.8 The great mental capacity divide

A recurrent issue raised in the interviews was that of whether other agencies ‘wanted’ or ‘didn’t want’ self-neglecting people to ‘have’ capacity. This is a quite extraordinary suggestion, yet it was voiced many times. Participants were effectively suggesting that the assessment of mental capacity was being manipulated for organisational reasons, rather than being based on the abilities of the individual involved. This is completely contrary to the MCA.

6.8.1 Agencies wanting people who self-neglect to be found to *have* mental capacity

Several reasons were articulated to support the belief that some agencies actively wanted service users to have capacity to make decisions. This is a very serious claim to make, as it is striking at the root of the professionalism and veracity of the assessments by the practitioners involved. Many participants felt that it was mainly social services who wanted this, and resentment was expressed,

> It was a gift to some people, the legislation saying that capacity will be assumed unless you can prove otherwise. (Housing Officer)

The belief that the MCA was gamed to further the objective of saving money was expressed by several participants, with the suggestion was that this was a quite deliberate ploy,

> Their resources are so strapped that it's in their interests to not detect any self-neglect. (Housing)

This group of community nurses related it to a wider political agenda, but also felt that capacity was not assessed honestly,

> R1: It's very political really though isn't it, capacity, because incapacity costs. And if it's going to lead to care, and if somebody's ticking along in their own home, and ... I'm very pessimistic about the government and things like that.
> R2: I think sometimes it's a bit of a cop out as well, oh, he's got capacity ..
> R1: I don't mean it's political, but because the funding isn't there, 'we can't deal with it', 'we can't deal with it', 'we can't deal with it', what can we do? If somebody is borderline, isn't it easier to say 'no, they've got capacity' let's just tick along with community nursing on this one because we're NHS and ..' (Community Nurses)

The ‘cop out’ was similarly expressed by others,

> It's generally used to just, to dismiss people. They've got capacity to make those decisions, you know, and that's the end of it (Homelessness Services)

This led to a feeling that it was pointless to refer people who self-neglected to social services because having capacity would be used to decline to act, which could result in a farcical cycle,

> It always comes back, 'no, there's nothing we can do, they've got capacity, just got to let them get on with it' and then it just keeps revolving and revolving, we keep putting the referral back again and it comes back, bing bong! (Community Nurses)

However, it wasn't just social services who were singled out for doing this, other agencies were also seen as using the MCA to permit inaction,

> Yeah, if the person does have capacity it gives other agencies the green light to almost go 'oh well, it's their decision, got capacity, they've made that choice, that's how they want to live', so it almost gives the agencies a green light to do that. (Fire Services)

For one participant, a finding of capacity meant that other agencies would withdraw,

> Because it closes down an avenue of action that might be able to be taken to help that situation, and all eyes look to you, 'well, they've got capacity, so it's over to you, deal with it. (Environmental Health Officer)

It could also contribute to the status issues mentioned earlier, whereby,

> 'In relation to the MCA, what we do get is to a degree professional snobbery does kick in.' (Housing Officer)

6.8.2 Agencies wanting people who self-neglect to be found to *lack* mental capacity

The reverse of the views expressed above were expressed by other participants and agencies (mainly, though not only, social services) who held the view that other agencies wanted people who self-neglected to *lack* capacity,

> They also think that if they do lack capacity that it's a done deal (Social worker)

Some of the reasons given for wanting people to lack capacity, were exactly the same as the reasons for wanting people to have capacity, and these reasons were predominantly financial,

> It's almost a kind of, they feel it's a tick box, 'well, they were neglecting themselves at home, they haven't got capacity, so surely you've got to look at placement (Advocate)

However, a finding of lack of capacity was also a way of abdicating responsibility,

> It's passing the responsibility, that's what it is. As soon as you say they haven't got capacity, somebody's got to take responsibility for them... (Social Worker)

Alternatively, finding lack of capacity permitted intrusive intervention,

> I think sometimes where people lack capacity but they've had a lifestyle previously for a long term when they did have capacity, sometimes professionals want to go in and take

> over because, they think they haven't got capacity, without recognising what that person's wishes were previously (Social Worker)

It could also be the easy way out, though still leading to conflict,

> … you know, if we say that person hasn't got capacity, it's almost easier when they haven't got capacity, when you do the assessment, and you go, 'result - no, they haven't got capacity, so let's all charge in here and let's all squabble'. That's an easy scenario. (District Nurse)

The situation around the perceived manipulation of the MCA in relation to people who self-neglected was therefore revealed as being extremely complex, to the extent that practitioners were ascribing Machiavellian motives to others,

> They think we don't want them to not have capacity. (Housing)

6.9 Management of conflict

> A lot of times we have arguments around capacity (Social worker)

Perhaps unsurprisingly, many of the issues described above led to conflict between agencies who were working with people who self-neglected, particularly in relation to the MCA. The metaphors of fighting and battle were often used by participants to describe this conflict. Laider (1991, p4) identified the possibility that 'interlocking of our strengths and weaknesses can lead to skirmishing or even war' and this was borne out here,

> R1: On occasion we have argued with other agencies as well.
> R: What we're saying is we'll argue with anyone [laughter].
> R1: Yes, we'll fight with anyone. (Community Nurses)

Participants described 'unbelievable conflict' (Occupational Therapist), and a 'constant battle' (Community Nurse), which had a detrimental impact on service users,

> Too many resources are going into the battles that we have rather than using that time and effort to our customers and our tenants. (Housing Officer)

Various 'techniques' were described by participants as to how they dealt with the conflict. These included,

- Irritating others into action: 'I'll hassle, harass them to death'. (Domiciliary care worker)

- Deploying the most tenacious team member: ‘I think certain staff members are a lot better at it than others who will cling on, and not accept the answer of ‘the person hasn't got capacity’. (Fire & Rescue Services)

- Playing ‘them’ at their own game: ‘Do they have capacity in that, not that, so I threw that at them, so it did, it helped, really helped’. (Domiciliary Care Worker)

- Going over their heads: ‘the only way we could move it forward was by speaking to the person’s manager, "we're really concerned.“’ (Housing Officer)

- Strengthening the case: ‘What we usually do is try and gather additional evidence. I included photographs that made it more difficult for them to ignore’. (Housing Officer)

- Brinksmanship: ‘my feeling is though that they'll push that forward first though to see whether you buy it or not.’ (Social Worker)

- Blinding them with science: ‘I think as well as snobbery, there's a bit of fob-offery [laughter] as well. I think if I use all the fancy terms and jargon they won't know what I mean, they'll just stop asking.’ (Housing Officer)

- Using their language: ‘because we’ve got the legal definition to be able to throw…throw in their face sounds a bit aggressive, but sometimes you have to use their language to get them to listen to you and so now we’ve got a definition that we can utilise and say well they’re meeting the self-neglect criteria because of this, this, and this.’ (Housing)

- Being strategic: ‘Depends who it was! You'd do it very differently wouldn't you?’ (Community Nurse)

- Using evidence: ‘You have to supply the evidence in an objective manner, it's all about the evidence. ‘(Occupational therapist)

- Going mob handed: ‘sometimes if you’re one agency shouting in the dark saying ‘this isn’t right’ you can be ignored, but if there’s four or five different ones all saying the same thing then it’s more difficult to ignore then because there’s the weight of other agencies. You can’t just say it’s just housing trying to pass the buck or something.’ (Housing Officer)

It was clear that much of the conflict was around the assessment of mental capacity in relation to people who self-neglected,

> Well, we generally have quite a battle with the idea of capacity and more important, the decision. (Advocates)

For some groups, their lack of expertise meant that they found it difficult to challenge the capacity decision of others,

> But we're not the experts in it, so, I think we feel like we're fighting a losing battle with it, because we're not the experts. (Housing Officer)

However, one group who declined to undertake capacity assessments themselves, nonetheless were happy to challenge those who did,

> We're not trained at all in terms of capacity but in terms of challenging, alright the person's got capacity, however, we're still telling you we've identified a problem, capacity or not, there's still an issue there. (Fire Services)

It was clear that mental capacity in relation to self-neglect was a huge challenge and source of conflict for practitioners who took part in this study. It led to considerable frustration,

> I'm looking at that doctor and wanting to stab them in the eyes and say 'you haven't tested their capacity, have you? Because they don't even know what's wrong with them, so how can they have made a sensible decision about whether they are safe to be managed at home? (Community Nurse)

6.10 Conclusion

In this chapter I have presented the findings from the first stage of the research. I have described firstly the initial ‘Headlines’ that I developed, very much at a semantic level, in order to feed back to the LSAB’s, and to progress the AR cycle. I have then provided a more in-depth analysis of the data from the interviews, group, individual and paired, which I carried out. In this I have combined elements of inductive, deductive and abductive analysis (Brinkmann, 2014), the latter asking of the researcher, ‘what are you surprised by? (ibid). As I became more and more familiar with the data, and in the process of coding and arriving at themes, I was increasingly surprised by the confusion caused by the MCA, the fear that practitioners expressed, and the levels of conflict and criticism that were revealed, and I will return to these in chapter 8.

However, I was also encouraged by all of the constructive ideas which were put forward by practitioners about how their practice could be changed to improve outcomes for the self-neglecting people they were working with, and the high levels of care and compassion that practitioners brought to their work. In the next chapter I will discuss how I took account of all of these factors in designing and carrying out the next AR cycle.

Chapter 7 – Action phase: *how* can changes to practice be made?

7.1 Introduction

In previous chapters I have described how, in terms of the Lewinian action research spiral, I began to identify the problem focus for this research from the pilot study I had carried out. I continued into the 'fact finding' or 'problem-sensing' stage (Hart & Bond, 1995), with the group and individual interviews conducted with the range of professionals who work with people who self-neglect. In the preceding chapter, I described how analysis of the data from the interviews revealed confusion, fear and conflict amongst practitioners in relation to multi-agency working and self-neglect. However, I also described the constructive ideas put forward by practitioners about how practice might be changed to improve outcomes for the self-neglecting people they were working with. With this wealth of ideas, I therefore had to consider carefully how to proceed into the next stage of the AR cycle, the action phase, and this chapter will detail this process.

7.2 Planning the next action step

In Chapter 5, I discussed how a definitive plan of work must usually be produced very early in the research process in order to gain approval for research to begin. This can be difficult for an action researcher to achieve whilst maintaining an AR ethos. The dynamic nature of AR means that it can be difficult to be prescriptive at the outset of the research about what later action phases may involve (Hart & Bond, 1995; Stringer, 2014). How could I set out a plan, as required for ethical approval, before I had carried out the problem-sensing phase? In my original ethics application I had written that the decision of how to proceed might be influenced by potential organisational changes in my participating local authorities. I had tentatively suggested that the next phase would involve action learning sets (Revans, 1998), one in each local authority, to focus on the main issues emerging from the interview phase. I had envisaged that each set would comprise 6-7 people, this being the optimum number for meaningful participation and successful outcomes (Abbott & Taylor, 2013), and would meet 4-6 weekly for up to 10 sessions (ibid). However, after the problem-sensing phase, several things had become clear:

- Action learning sets, comprising 6-7 people would not be large enough to encapsulate the complete multi-agency picture as it has been presented to me running the group interviews. In addition, could be a risk of simply replicating traditional patterns of 'silo working' (Noga et al, 2016, p9).

- The group interviews had proved exceedingly difficult to organise, because of the demands on participants' time, so it was very unlikely that people would be willing and able to commit to 10 sessions of an action learning set, even if this were done 'virtually'. Additionally, Noga et al (2016) note the difficulty of getting people to do work outside of the sessions.

- The nature of the issues identified meant that there was not a clear task for an action learning set to focus on. There was still a great deal of work to do on prioritising ideas and realistically considering *how* changes to practice might be made.

- Although action learning and action research may appear similar, Edmondstone (2018) argues that the two have fundamentally different approaches. Action research is 'generally a cyclical and iterative research approach, conducted within specific and often practical organisational contexts' (ibid, p195), whereas action learning is, Edmundson argues, a more general approach to learning (ibid). I began to see that I was in danger of blurring these differences of perspective, and that I had not understood this delineation clearly enough when I had written my original research proposal.

I needed therefore to amend my plan in light of my experiences.

7.3 Multi agency participatory workshops

For the first action step, I therefore proposed to hold multi-professional ‘Get Together’ events (Fleming et al, 2014), in each local authority that had participated in the research. The aim of the events was to share the data that emerged from the first phase, in relation to what professionals considered needed to change in multi-agency working in self-neglect, consider the relative priorities of these areas of practice, and to focus on *how* attendees considered that changes could be made (Gray, 2014). I wanted to use a participatory AR approach, because it combines both critical reflection and participation (Baldwin, 2012), and allows ‘the collective investigation of problems … collective analysis of data…and collective action to yield solutions to identified problems’ (van Rooyen & Gray, 1995, p3). Martin (2006) notes the importance of such events in thinking through and planning change. McVicar et al (2012) in their review of action research studies in nursing and social work, note that interactive events are a popular method where practice improvement is sought. Cameron et al (2014a) report that in their study, team building events and training were frequently identified as helping to build a common sense of purpose, and Head & Alford (2015) suggest that the participation of a wide range of actors, such as a well organised multi-agency workshop could provide, will offer different insights into why a ‘wicked’ problem emerges.

Lifvergren et al (2015) use the term ‘democratic or development dialogues’(p336) to describe large systems meetings which aim to generate systems change and produce plans for joint action. I used the term ‘workshops’ to describe what we would be doing, as I felt this more accurately captured that there was work to be done. I also always described them as ‘participatory’ (for example, in recruitment literature, see Appendix 6), to give the clear message to potential participants that this was not conventional training where they were going to be taught how to do something, and they were not going to be the passive recipients of knowledge, as defined by Freire (2010). This was active, rolling up of sleeves and taking part.

Reflective stop off

The very positive aspect of running many different group interviews was that many people had been involved, and of these, many had expressed a desire to be involved further. I wanted to capitalise on this momentum. Bringing people together, helping them to understand one another's roles better, and providing opportunities to share experiences had all been identified by participants in the group interviews.

In a sense, I could kill two birds with one stone. Not only could I bring people together in a multi-professional setting to explore the issues that had been raised in the uni-professional interviews, but the very act of bringing people together, to allow time and space for conversations (Gudnadottir et al, 2018; Sloper, 2004) was a response to a need raised by the participants thus far, and valuable in and of itself.

As described in the previous chapter, I had found high levels of conflict and frustration being expressed by practitioners with a shared profession in the group interviews. I found Allport's concept of the Contact Hypothesis (1954) useful in informing my thinking about holding workshops specifically as it has been applied to interprofessional learning and education (Hean & Dickinson, 2005; Michalec et al, 2017). Put simply, Allport (1954) suggests that the best way to reduce hostility between groups is to bring them together. However, Allport (1954) argues that there are key conditions which must be in place for this to happen. These include that groups must be working together towards a shared goal; there must be interdependent, inter-group cooperation; groups must have the support of the institutions involved; group members should have positive expectations: group members must see each other as typical members of their group; they must understand the differences and similarities between groups; and the groups must have equal status. The first five conditions could be satisfied by using workshops for the next cycle of the research. The final two however, both of which had come up as issues in the interviews (expressed as ‘not understanding each other’s roles’ and ‘professional preciousness’) were not givens. I needed to reflect on this in my preparation and planning, particularly in relation to how to minimise any conflict that might arise. This had been strongly indicated during the interviews, and was a concern of mine in moving from homogeneity to heterogeneity of participants.

7.4 Feedback to the safeguarding boards

In the previous chapter, I discussed the requirement to feedback information from the group interviews to the Local Adults Safeguarding Boards, in order to gain their agreement to progress the research further. For this purpose, I had developed the change ‘Headlines’ identified by participants (see section 6.2.1). I prepared short PowerPoint presentations for each of the Boards, sharing these Headlines. However, in the previous chapter I also discussed the wider abductive findings, which raised issues in relation to conflict, fear, and operationalising of the Mental Capacity Act. I felt that both aspects of the findings needed to be fed back to the Boards, in order to give them the full picture of what was emerging. I also felt that the wider issues could not be ignored in whatever future work I did with participants, as it would not have been a truthful reflection of what they had shared with me. I owed a responsibility to my participants to be honest about what had come out of the interviews. However, I also realised that some of these issues might be unpalatable hearing for the Board members.

Kemmis (2006) describes how one of the key roles of the action researcher is to be what the ancient Greeks described as the *parrhesiastes*, the person who ‘brings unwelcome news or tells uncomfortable truths’ (p461), and who will require courage and conviction to speak honestly. He argues that this is ‘an integral part of the obligations and duty of the critical action researcher’ (ibid). Therefore, feedback to the Boards also included indication of the wider findings. The following extract from my Journal gives some sense of what Kemmis describes.

Journal entry

Went to the Board meeting. Felt it went ok, but only ok. As usual a very packed and rushed agenda. It was not chaired by the independent chair I had met before. This was a great pity, as the substitute chair did not know anything about the research. The head of safeguarding was not present, which was also a great blow, as he had said he would back me up and talk about what we/he was planning to do next. I was very nervous and felt very isolated. I felt I had to be incredibly diplomatic in what I was feeding back, but even so felt that I was sounding rather critical and like a consultant giving recommendations, though I had tried to emphasise what people felt needed to change, rather than talking about how that change might happen.

I proposed feeding back to participants at a multi-agency learning event. I said that this would be to try to develop an action plan to take some of the changes forward, looking at what is important and what is do-able. I was trying to stress that this all needed to come from practitioners, but I could feel it slipping away from asking practitioners themselves, to the Board deciding what to do for them.

Argyris (1985) considers the problems of feeding back difficult results and the necessity for the researcher of understanding defensive patterns that may be displayed. The Boards themselves were multi-agency entities, and thus there was no reason to assume that there would not be levels of conflict and mistrust between the organisations represented. Argyris argues that researchers may be required to tell clients (sic) that they are behaving in ways that may be counterproductive to effectiveness. To do this, they need to ‘deal with the differences between clients and researchers in ways that join with clients rather than polarising against them’ (p204). I tried to do this by not in any way seeking to cast blame on individual agencies, and by anonymising all of my presentations. It was also reassuring to know that, as far as Argyris (ibid) was concerned, defensive routines were to be expected.

Hart (in Hart & Bond, 1996) describes her experience of the conflict between whether her role was that of management consultant or academic researcher, and I could very much relate to this. She also argues that professionalising AR can be vulnerable to ‘usurpation by the managerialist agenda’ (p158), and I would concur with this. I had to be very clear that I was proposing running participatory workshops rather than training, to which senior management might have been more amenable (particularly if it were cost free).

Despite these difficulties, both of the Boards agreed to the workshops taking place, and as this meant the numerous agencies involved making a further commitment to the research and, as a minimum, releasing their staff for a morning or an afternoon, I was very grateful for this. They also agreed to provide venues.

7.5 Developing the workshops

Two workshops were planned in each authority, for a maximum of 30 participants per workshop. I felt this number was small enough to enable good whole group discussion, but large enough to allow for small group work. They were advertised as being open to anyone working with people who self-neglected (this was also the original inclusion criteria for the interview phase). I hoped that this would attract both practitioners who participated in the first phase (focus groups or interviews), and practitioners who may not have participated in the first phase, but who were in the professional groups who work with those who self-neglect. This would help ensure credibility in terms of member checking and peer scrutiny (Shenton, 2014). However, it also meant that participants would be much less likely to know one another, as they had done in the group interviews. This difference between ‘strangers’ and ‘acquaintances’ (Morgan, 2013) was potentially an important one, and as Morgan notes, researchers need to consider whether particular group of participants can comfortably discuss the topic in ways that are useful to the researcher, when they are strangers to each other.

7.5.1 Recruitment

I had feared that recruitment for the workshops would be slow and difficult, as it had been for the interviews. However, in practice, with the help of allies (see below), and the contacts which I had also developed by this time, I was inundated with applications. The workshops were heavily over-subscribed, particularly by social workers. My difficulty lay in ensuring a good professional mix from the numbers who applied, and in effect, I used purposive sampling to do this. I noted in my journal that:

> **Journal entry**
>
> An interesting thing is happening with the workshops. I cannot control which grade of staff come, as they were advertised as being for everyone. However, it is very noticeable that from health care I am overwhelmed by community matrons, senior ones at that! Now, none of them were involved in the focus groups, the staff were much more humble … but in terms of the research, the community matrons would probably be the ones who can get things done. So that leaves me with a dilemma – no lower grade staff, who are the ones who work with self-neglecting patients on a daily basis, but people who can make the changes are coming. There are some support workers and less senior people coming, but, for example, no 'just' community nurses. I suppose that, ironically, it was probably easier for nursing teams to sit down with me for an hour over lunch for a group interview, than it was for them to be able to spare staff to come to a half day workshops, which more senior staff might customarily attend and then feedback to the team at a later date. It is a good example of how the voices of those on the ground, at the front line, can simply get lost.

In terms of Allport's (1954) pre-conditions, mentioned above, it did also concern me that these more senior staff were not seem by others as typical of their respective groups, as Hean & Dickinson (2005) note that this can hinder small group work. It would be interesting to see how this worked out on the day.

7.5.2 Ethical approval

Because the research had developed since my initial application for ethical approval and I had amended my original research plan, I was required to submit a further ethical approval application to the university in order to carry out the participatory workshops. I also had to re-visit the approvals I had obtained from the health trusts and others. When information about the workshops was circulated in LA1, where the health trusts are not coterminous with the local authority boundaries, I had applications for places from people working for Trusts for which I did not have ethical approval, and these applicants had to be refused. This was frustrating for me and for the participants involved.

7.5.3 Timing of the workshops

The interview phase had shown me that for some professional groups, the issue of timing is very important. Nurses told me that they found it difficult to attend any meetings or other events in the mornings, as this was their busiest time. Paramedics had to arrange any events such as training, or participating in research, in their own time, outside of their working hours (a very strong disincentive for their participation). Police and Fire Services have to cancel at the last minute if a priority incident occurs (as it did at one workshop). Hospital-based staff were restricted by other timetabled commitments, such as ward rounds or clinics, or simply by shifts starting or ending. Therefore, to get multi-agency participation, these simple but crucial barriers to participation must be considered by the researcher.

7.5.4 My role as facilitator

Facilitating the workshops was a very different role for me than running the group interviews and it brought me back to considerations of my own positionality. How did the facilitator role differ from that of a teacher or a trainer? As I wrote in my journal:

Journal entry
I'm struggling to identify the aims of the workshops, and thus am falling into the trap of making them a teaching session. Because I know a lot about self-neglect, it's really tempting to want to just share all that, and fall back on chalk and talk. But instead I've got to be clear about what my aims are, and how they extend the action research, and how the workshop is about coming up with a plan for a way forward My problem is I know that I could deliver a great training session, and I'd really enjoy doing that, and the participants would like it. BUT that's not what I'm there to do. I need to just 'shut up'.

facilitation is often understood in many different ways, and that people carry their own different beliefs about the nature of facilitation and the skills required, which are often unexamined and incongruent. She believes that it is not helpful to define oneself as a particular 'type' of facilitator (e.g. supportive or challenging), but to be able,

> to embrace the paradox of valuing both ends of the spectrum [of facilitation skills and styles] and acting in a timely, elegant and skilful way at both ends of the spectrum of polarities and indeed at finally graded points anywhere along the spectrum. (p617)

This is the 'lively and personally demanding' (p618) action research in the moment, whereby facilitators are 'continually asking themselves, and sometimes the group, what is needed here' (ibid). This seems to me a perfect example of Schön's (1987) concept of 'reflection in action'.

Mackewn (ibid) suggests that there are four dimensions to be considered by the facilitator; the purpose of the group, the facilitator's theoretical conceptualisation of group processes; the wider system in which the group is located; and finally, 'choreography of energy' (p624). This latter dimension, Mackewn sees as the most important, as it relates to working with the 'energy flows in a group' and is a 'meta-skill' (p624). I will return to these points later in this chapter. Hart & Bond (1995, p198) provide a practical list of factors to be considered by facilitators of groups in AR projects, and I found these helpful.

7.5.5 Working with co-facilitators

Following the group interviews in LA1, a public health consultant within the authority contacted me. He had heard about what I was doing, and my proposal to the Board to run the workshops. Self-neglect was a priority that had been identified for the Public Health department, and he was keen to become involved. He also introduced me to the lead safeguarding nurse, who similarly was keen to be involved. The LA had recently commissioned a 'Learning review' into a serious self-neglect case, and were eager for an opportunity to share the learning from this case in a multi-agency forum. Thus, both workshops in LA1 were co-facilitated to an extent, and included feedback from the learning review. In LA2 I facilitated the workshops singlehandedly, and the learning review was not included.

7.6 The workshops

7.6.1 Aims of the workshops

As described above, the aims of the workshop were:

- To share the data that emerged from the first phase, and for participants to analyse this data further
- To check with participants that the 'Headlines' were a good reflection of what they felt needed to be changed
- To prioritise the changes that participants had identified, in terms of importance and 'do-ability'
- To begin to plan *how* the suggested changes could be made.

Although I knew what I wanted the workshops to achieve, it took me a long time to design their format. I was anxious to engage participants fully, I did not want to bore them, but I also wanted them to challenge them to participate. Mackewn (2008) encourages creative approaches, which;

> take people just outside their comfort zone, but not into their panic zone; to give a really good relevant and rational reason for why you are suggesting they try this (so that their rational mind is settled) (Mackewn, 2008, p627).

7.6.2 What we did in the workshops

Each workshop followed a roughly similar format, with an icebreaker, followed by five key tasks. During the workshop, I might make small adjustments to the format if timings were going astray, or if participants were particularly interested in an area of discussion that it did not seem appropriate to end too abruptly. This was ‘action research in the moment’ (Mackewn, 2008), and it was exhausting. At the end of each workshop, I reflected on what had worked well and what had not been so successful, and made some changes where I felt this was necessary, following the AR cycle. Changes might be to ordering, or presentation style, or materials used. However, all four workshops worked on the same key tasks.

Workshop schedule

Welcome and setting the context -

Icebreaker: Clickers quiz – how clean are you? (Whole group)

1. **Matching Headlines with what people said (Small groups)**
2. **‘Ranking the headlines’ task - from the list you have, select the top 5 (Small groups) ‘What is important and what is do-able?’**
3. **World Café whole group task – how can we begin to put changes into practice? (Whole group)**
4. **Mental Capacity – what changes could be made?**
5. **What next? Changing one thing in your own practice – postcards (Individual)**

Figure 12: Workshop Schedule

7.6.3 Icebreaker quiz

Although this was not a task, I used a short quiz which I had devised, ‘Cleanliness is next to Godliness’, (See Appendix 7) to establish with participants the underlying difficulty of differing individual personal standards in working with people who self-neglect. Its purpose was to try to get participants to see that current social practices are neither natural nor inevitable (Ozanne &

Saatciouglu, 2008), and to encourage them to question the construction of 'cleanliness'. I also wanted to establish that this was a safe space in which to discuss difficult issues.

Questions were designed to reflect some of the common problematic areas encountered with people who self-neglect, such as not bathing or washing hair, not doing housework, disregarding food hygiene, and so forth, though in a humorous way. The classroom response technology that I used enabled participants, using a small hand held 'clicker', to anonymously select and answer each question and for the collated result of each question to appear immediately on the screen. The quiz functioned extremely successfully as an icebreaker.

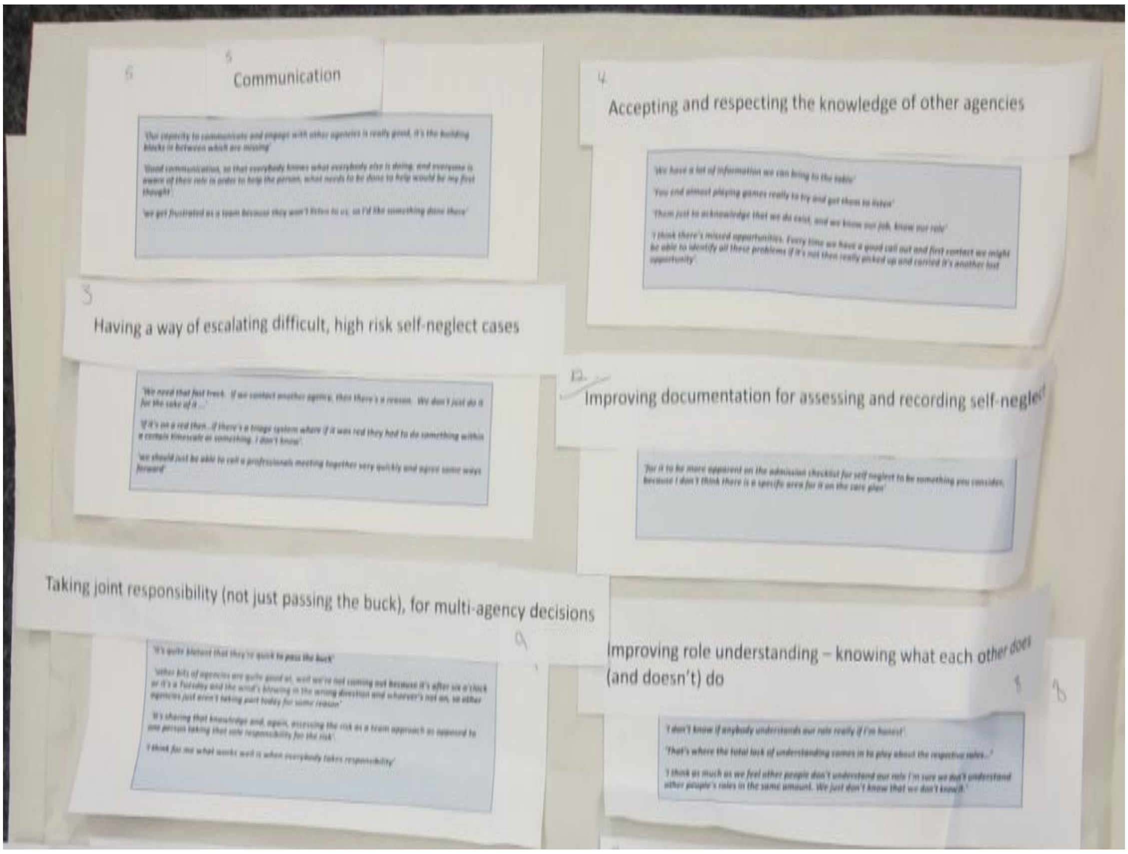
7.6.4 Task 1: Matching Headlines with what people said

As mentioned in the previous chapter, by analysing the data myself I had made decisions about which aspects to focus on and how to read and make sense of the data (Steffen, 2016; D'Cruz & Gillingham, 2017). However, I wanted to use the workshops as an opportunity for some form of participatory data analysis, to see whether my interpretations of the data would 'ring true' with those who provided it (Herr & Anderson, 2015). The literature around participatory data analysis seems to suggest that this is much more commonly used for analysing quantitative than qualitative data (e.g. Nind & Vinha, 2016; Public Profit, 2016), and indeed, as Herr & Anderson (2015) note, 'Many wonder how collaborative data analysis works in practice' (p117). D'Cruz & Gilligan (2017) describe involving participants in data analysis as a 'fraught and challenging process' (p445), and that ultimately participants will have to accept the dominant research paradigm. However, Herr & Anderson (2015) believe that the importance of participatory data analysis is to get participants thinking about the usefulness of the data that has been collected, and that is what I aimed to do.

I could see that participatory data analysis could raise serious issues of confidentiality. It would not have been appropriate for participants from one group to analyse the data of another group directly, as it would have the potential to deepen and entrench their attitudes towards each other. What was important were the shared frustrations expressed by the various participants, rather than what they said about each other (which could be very negative indeed).

Thus, when I was introducing the idea of the Headlines at the workshops, I told participants that I had deliberately chosen quotes to illustrate the Headlines that were *not* said by the group that might have been expected to say them. So if they read a quote and thought ‘oh, that’s a typical nurse talking’, then it probably was not. Although this strategy could be criticised for me censoring the data (Guenther, 2009) which might be against the spirit of an AR project, in practice, I felt that participants rather enjoyed this element of me ‘calling their bluff’. I also used examples of the same thing being said repeatedly (e.g. in relation to the theme of ‘battling’) so that who had said it became less important than the number of times it had been said.

The task that participants undertook was as follows. Firstly, I gave a general introduction to the Headlines and explained how I had arrived at them through my initial analysis of the data from the group and individual interviews. Then in groups of 5-6 people, they reviewed the Headlines definitions (the codes for the theme ‘Can we try to change it?’ discussed in the previous chapter), by matching them with original, anonymised quotes from the data. This was in line with the process suggested by Tandon et al (2001). Participants reviewed headlines and quotes for clarity, comprehensibility and relevance, by reading them aloud. This allowed them to get a flavour of the authentic voice, of what their colleagues had actually said, the expressions they used, and so forth. As Herr & Anderson (2015) put it, this provided ‘a better sense to participants of the relevance and meaning of the codes’ (2015). They then had to decide which quotes matched which Headline (see figure 16, below). In informal discussion with groups as they worked on the task, I asked them if they identified with what was being said, and whether they agreed with it, or felt there were omissions. This was a form of member checking, a component of credibility (Shenton, 2004).



Communication

Having a way of escalating difficult, high risk self-neglect cases

Taking joint responsibility (not just passing the buck), for multi-agency decisions

Accepting and respecting the knowledge of other agencies

Improving documentation for assessing and recording self-neglect

Improving role understanding – knowing what each other does (and doesn't) do

Figure 13: Matching Headlines and quotes (extract)

7.6.3 Refining the Headlines – what participants suggested

At the first workshop, there were seventeen Headlines that I had developed from the data. However, discussion between participants showed me that some of these were confusing and overlapping. Comments from the first workshop prompted me to collapse some codes together in a way which made more sense to the participants. Thus 'Multi-agency training' was felt to be a way of improving role understanding, but not a change that was needed in and of itself. 'Making contact and engaging with service users' was felt to be the same as 'low level support for people who self-neglect'. 'Better demographic data' was felt to be irrelevant. 'Shared IT systems' and 'more money' were seen by participants as important, but outside of their control. Therefore, we amalgamated or abandoned some headlines at the first workshop, and for the next three workshops we worked with twelve headlines,

- Improving role understanding – knowing what each other does (and doesn't) do
- Taking joint responsibility (not just passing the buck), for multi-agency decisions
- Communication
- Making it easier to contact and refer to other agencies
- Improving referrals and information sharing
- Improving documentation for assessing and recording
- More multi-agency meetings
- More integration of domiciliary care/support agencies
- Aligning response times and timescales
- Having a way of escalating difficult, high risk cases
- Having a named care co-ordinator for high risk cases
- Improving contact, engagement and support for service users who self-neglect

I also reduced the number of quotes from the transcripts that participants were given to match up with the Headlines, because participants said that during the workshop that they were taking too long to read out and that I was giving too many examples to illustrate the point.

7.6.4 Task 2: Ranking the Headlines

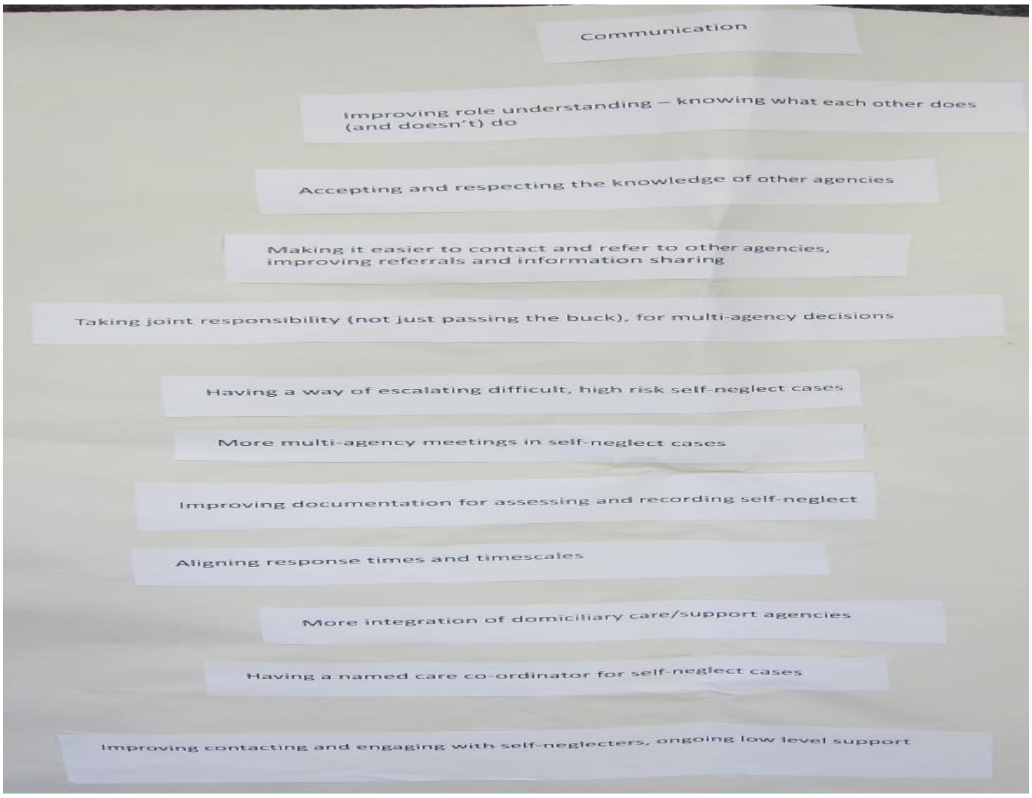
Having established with participants a sense of the relevance and meaning of the Headlines, in the next task I asked participants to rank the Headlines, as it was important to agree the priority areas for any change. They were asked to consider two things, the importance of each suggestion for change, but also the 'do-ability' of each suggestion.

Journal entry: Reflection after the first workshop

The ranking exercise worked very well. Lots of group discussion. One group wanted to join three categories together; another didn't want to put them in a linear way. I noticed that a couple of groups went back to the quotes, even though I hadn't mentioned doing this, to help them understand more about what each category mean. This was great. One participant reported conflict in their group about the order, though they managed to resolve this. Discussions were considered and thoughtful

Similarly, changes to IT systems, though important, were felt to be not do-able in this forum.

Figure 14: Participants at work



Communication

Improving role understanding – knowing what each other does (and doesn't) do

Accepting and respecting the knowledge of other agencies

Making it easier to contact and refer to other agencies, improving referrals and information sharing

Taking joint responsibility (not just passing the buck), for multi-agency decisions

Having a way of escalating difficult, high risk self-neglect cases

More multi-agency meetings in self-neglect cases

Improving documentation for assessing and recording self-neglect

Aligning response times and timescales

More integration of domiciliary care/support agencies

Having a named care co-ordinator for self-neglect cases

Improving contacting and engaging with self-neglecters, ongoing low level support

Figure 15: Task 2, Ranking the Headlines, Example 1

Some groups suggested alternative, non-linear ways of ranking, other groups identified overlap between categories. This allowed group discussion of the 'top' priorities for action, in terms of both importance and scalability. One group felt that the headlines could be divided up into 2 groups, where if you did A, then B would follow. As they wrote on their chart:

> Communication is paramount. By achieving A, B becomes possible and vice versa.
> A and B are equally important and achievable!

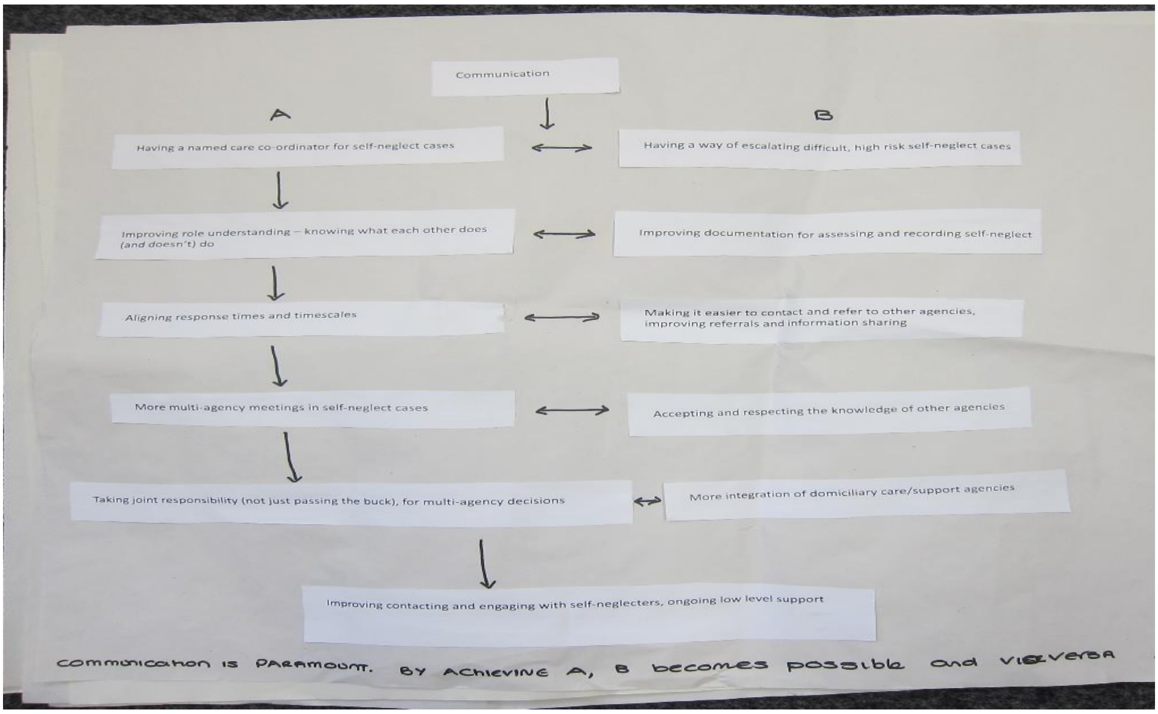


Figure 16: Task 2, Ranking the Headlines, Example 2

Reflexive stop-off: Action research in the moment
In the event, all of the groups at each of the workshops identified communication as their top priority. At the first workshop, this came as a huge surprise to me. However, it also concerned me, because I knew from the group interviews that 'communication' could cover so many areas and was nebulous and non-specific, particularly in comparison with other Headlines, and often given as a 'reason' why things could not change. I did not want to simply get 'stuck' with communication and nothing else. Therefore, I had to decide there and then (in the coffee break) whether to focus simply on communication as the area for change, or whether to deliberately broaden out the focus. I decided to do the latter by asking groups what their second priority was, so I could include this as well as communication as an issue to discuss further. This meant that for the next task in the workshop, groups were working on four or five priorities rather than just one. This was a pragmatic decision, made on the spot, 'action research in the moment'. I don't think there was a right or wrong decision to be made here, but I was trying to keep the research as full of possibilities I it could be, rather than prematurely closing down options.

group had decided were the priorities, and how they had come to that decision. I noted the top priority for each group, as this was needed for the next activity.

Table 9: Priorities selected by different groups at the workshops

LA1 Workshop 1	LA1 Workshop 2	LA2 Workshop 1	LA2 Workshop 2
Communication	Communication	Communication	Communication
Escalating	Escalating		
Multi-agency approach			
Making contact			Making contact
	Engaging with SU		Engaging with SU
	Care-coordinator		Care co-ordinator
	More meetings	More meetings	
	Improving role understanding	Improving role understanding	
		Improving documentation	
		Joint responsibility	Joint responsibility
			Accepting knowledge of others

This table shows the variation in priorities selected by the different groups over the four workshops. The variation in the number of groups at each workshops is related to the number of attendees. It is interesting to see that, apart from the consistency of communication as the priority in each workshop, a wide range of other priorities were selected, and they included ten of the Headline items. As can be seen above, some items were only selected at one workshop (for example, improving documentation), whereas others were selected at two workshops, one in each authority. These simply reflect the choices and decisions of the participants.

Two items did not appear at all as priorities, and were not taken forward into the next task. These were,

- More integration of domiciliary care/support agencies
- Aligning response times and timescales

The priorities identified will be discussed more fully in chapter 8.

7.6.5 Task 3: World Café whole group task – how can changes be put into practice?

Having identified the group priorities for change, the next step was to look in depth at how changes might be implemented, in order to begin to formulate an action plan. At this point in the workshop, it seemed important to get people moving around, talking to new participants, and to encourage creativity. World Café technique (Brown & Isaacs, 2005; Steier et al, 2015),

> fits well with the participatory worldview of action research, which makes relationships central to its practice. The World Café's reliance on creating dynamic networks of conversation around questions that matter to communities, is a form of meeting, as collaborative inquiry, that can serve as a rich resource for action research practice.' (Steier et al, 2015, p211).

I felt that a form of World Café technique (Brown & Isaacs, 2005) could usefully be adapted for the second part of the workshop. This involves setting up small groups in 'conversation clusters' to discuss the issues selected. People take part in several 'rounds' of conversation as they move from table to table, whilst a 'host' remains at each table to welcome participants, provide an overview of discussions so far, and to summarise the current discussion. Large sheets of paper and writing materials are placed on each table so that participants can write, draw or doodle thoughts and ideas (World Café Community Foundation, 2015). Ideally, a 'homely atmosphere' (ibid) should be created in which people can work.

Thus, during the break, I put large paper tablecloths on each of the tables, and plenty of marker pens. In the centre, I wrote one of each of the priorities that had been identified by the groups. I asked one spokesperson from the group which had identified that priority to stay with that table. I then asked people to get a drink and cake which I provided (this definitely helped the 'homely atmosphere') and go to a different table, with a different group of people. The spokesperson then briefly described to the group the thinking behind the identification of this priority. The group then began writing their comments on the tablecloths, and chatting to each other about how this change could be brought about. I asked them to consider how the change could be monitored and evaluated, what might help or hinder the change they were suggesting. This worked very well, and in the feedback, many people commented on how good it was to meet colleagues from other agencies, which they had not so much in the previous tasks when they were more confined to their groups. After 10-15 minutes, the groups moved on to the next table (with the original spokesperson staying where they were), and so on until they had been to all of the tables. Many excellent suggestions and strategies were identified as part of this task.

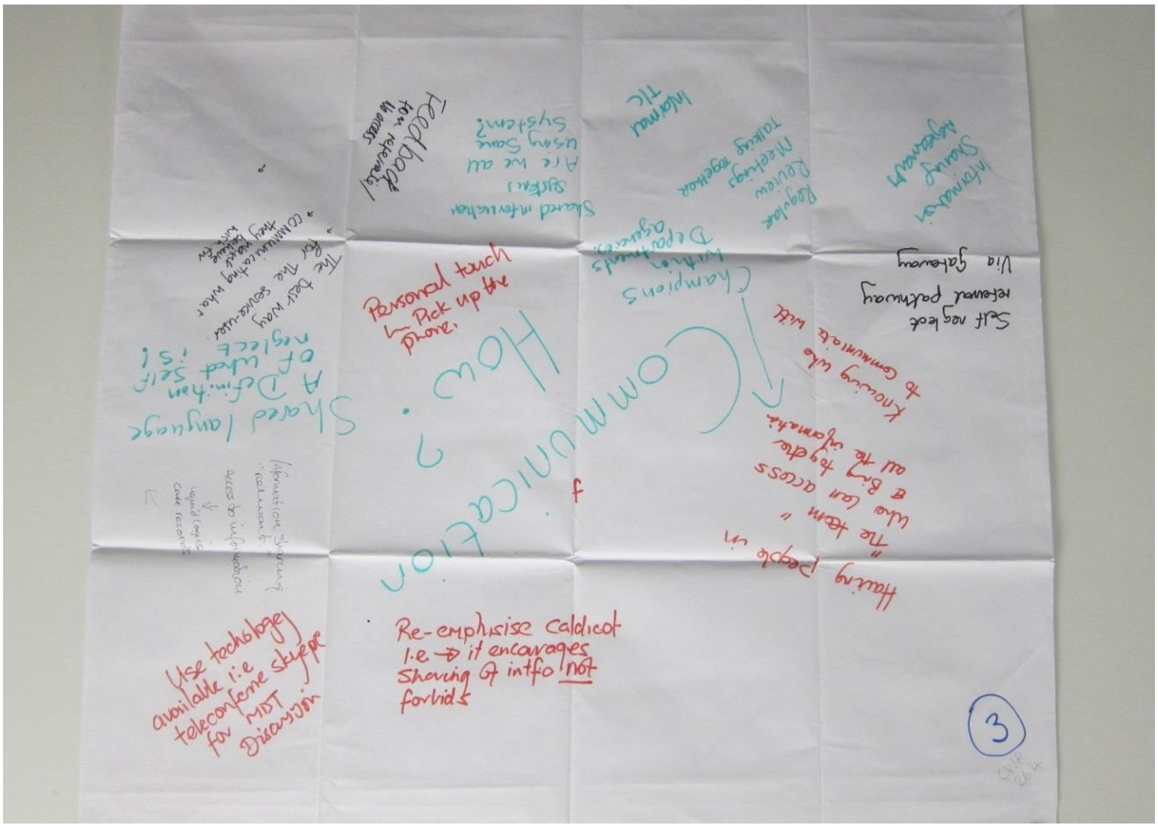


Figure 17: Task 3, World Café, Communication

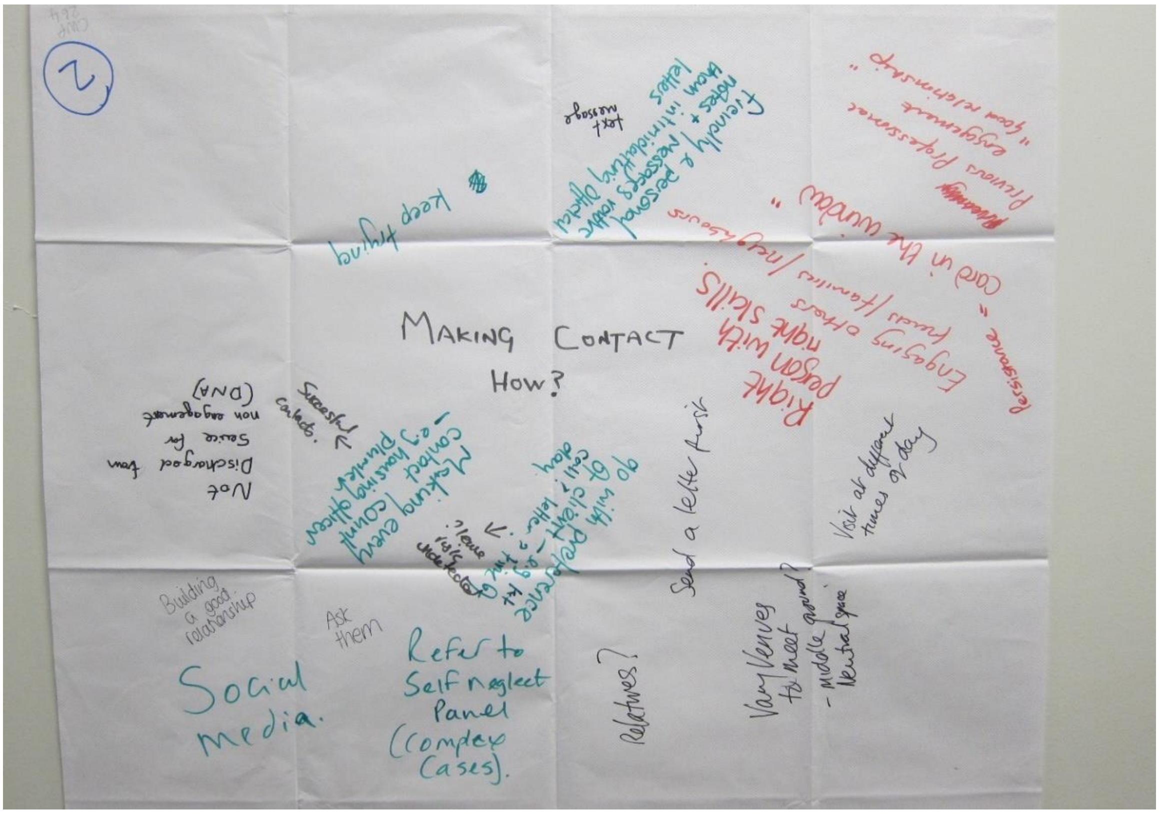


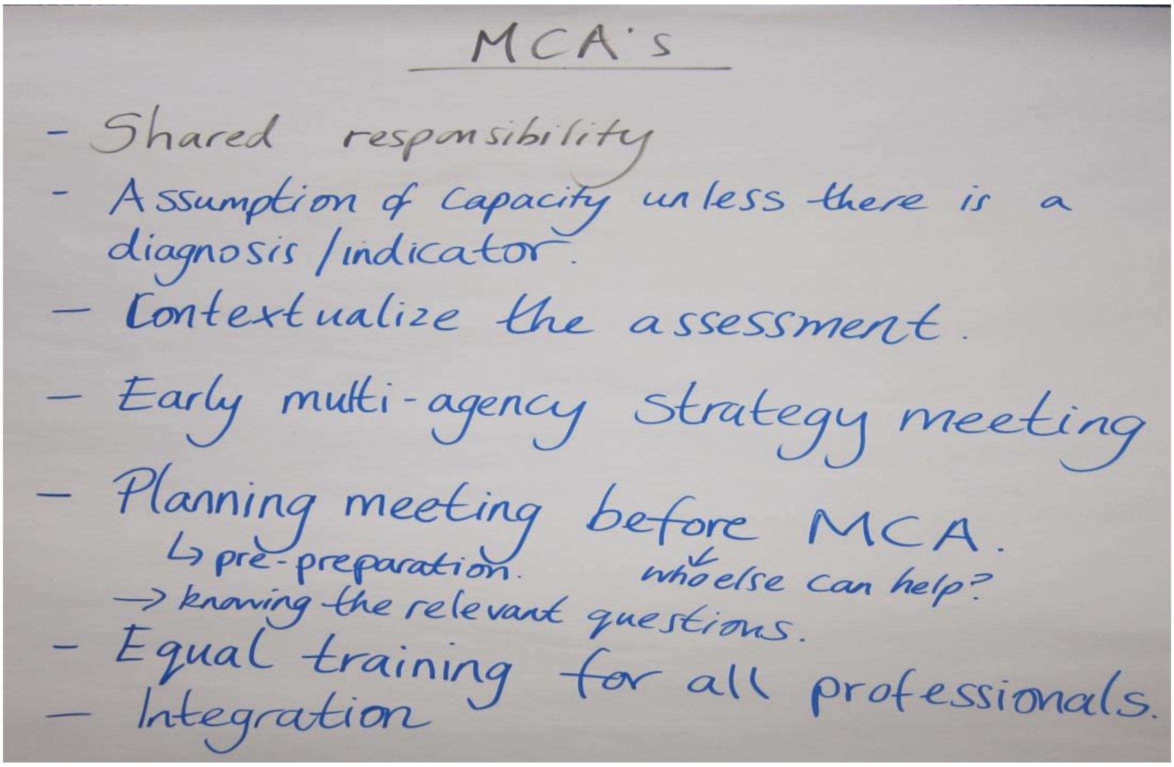
Figure 18: Task 3, World Café, Making Contact Easier

After each group had visited each table, we had further whole group discussion. The purpose of this was to get a sense of how participants wanted to proceed from this point with the changes that had been identified. However, this was perhaps the least successful part of the workshop. There was a sense from participants of ‘we have gone as far as we can’, and ‘more senior management than us would have to make these decisions’, and a definite reluctance to commit to anything further. However, I was also concerned that people might feel put ‘on the spot’ if pushed to commit to actions.

7.6.6 Task 4: Mental capacity: What changes could be made across all agencies, to improve the way capacity is being assessed for people who self-neglect?

> I think there’s a bit of a belief that there’s some kind of mystic voodoo about capacity (Participant)

The issue of mental capacity did not appear in the Headlines, which were the main focus of the discussions and work at the workshops, perhaps because participants in the group interviews did not see this as something that could be changed in its operationalisation. However, as described in the previous chapter, the application of the MCA was an issue that was discussed in all of the interviews and clearly caused participants a great deal of concern, in relation to their work with people who self-neglected. I did not feel that it could be ignored in the workshops. However, I was very concerned that too much emphasis on the MCA could lead to the main purposes of the workshops being lost, and to an expectation that this was a training session about the MCA rather than a participatory workshop. In the group interviews I had experienced participants asking me questions about the how the Act worked, and whether they were applying it correctly. I did not want to be drawn into the 'expert' role here. Task 4 therefore, simply aimed to get participants, in small groups, to suggest what changes could be made to the way capacity was being assessed for people who self-neglected. Many suggestions were made, and issues which had been raised in the interviews re-surfaced here.



MCA's

- Shared responsibility
- Assumption of capacity unless there is a diagnosis/indicator.
- Contextualize the assessment.
- Early multi-agency strategy meeting
- Planning meeting before MCA.
  - ↳ pre-preparation. who else can help?
  - → knowing the relevant questions.
- Equal training for all professionals.
- Integration

Figure 19: Mental capacity: what changes could be made across all agencies, to improve the way capacity is being assessed for people who self-neglect?

After the workshops, I was able to collate the responses to these discussions. I conducted a simple thematic analysis (Braune & Clarke, 2006) of these suggestions, which numbered just over fifty. I identified six recurrent themes in the participants' responses,

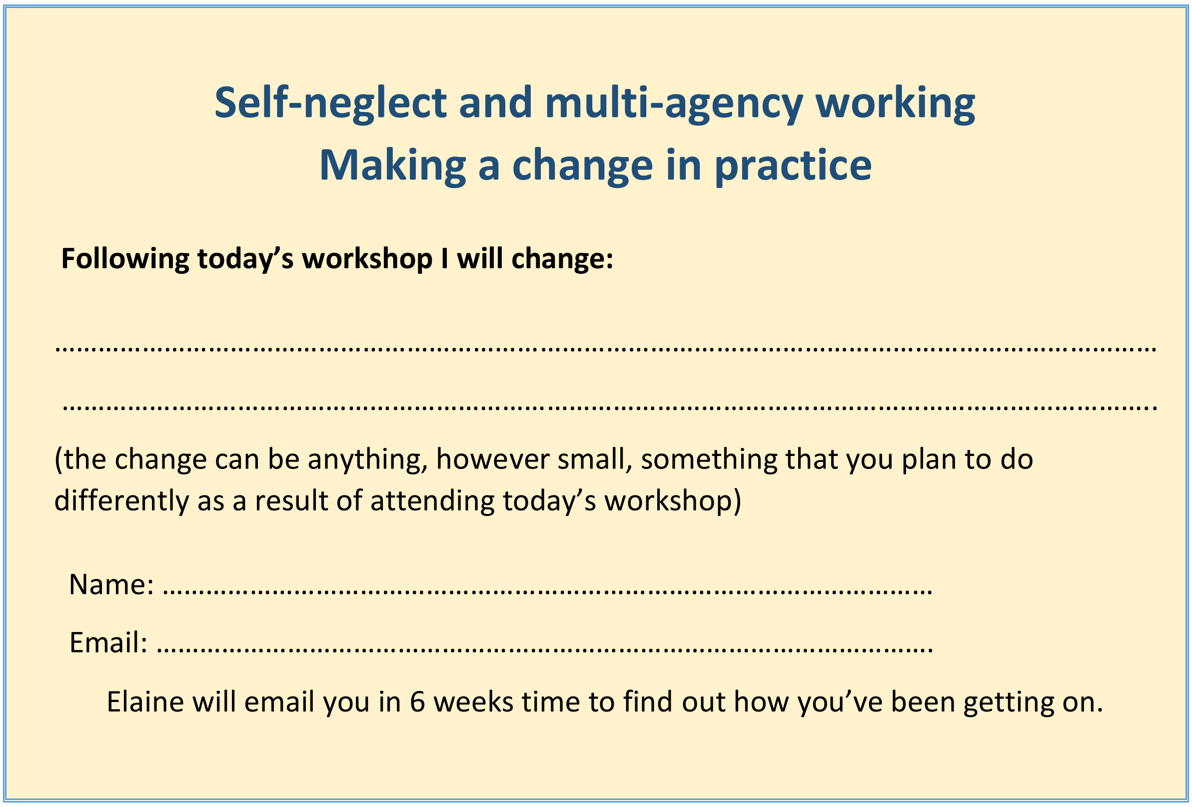
- The policies and processes that are followed
- How the assessments are done
- The training people receive:
- The documentation that is used:
- What is important?
- What is difficult?

7.6.7 Task 5: What next? Changing one thing in your own practice

In the four workshops, participants identified the top priorities for change in the way they worked with people who self-neglected. They considered in depth practical ways in which those changes might be made. Participants who were interested in being further involved in the research had indicated this, on the feedback forms that they were asked to complete at the end of the workshop. However, the way in which the research was to be taken forward on a wider level could not be definitely stated at the end of the workshops. I did not want to lose the momentum that had been generated in the workshops and the sense that had emerged that change *could* be made by participants. As Braun & Clarke (2013) observe;

> Taking part in a group discussion about a topic can have a 'consciousness raising' effect on individuals and lead to some kind of individual (and perhaps ultimately social or political) change (p111).

I wanted to try to capture whether this was true for participants. Therefore, at the end of the workshop, when people were filling in feedback forms, I introduced 'change promises'. All participants were asked to complete a card, on which they would write a change they intended to make to their practice as a result of attending the workshop.



Self-neglect and multi-agency working
Making a change in practice

Following today's workshop I will change:

………

………

(the change can be anything, however small, something that you plan to do differently as a result of attending today's workshop)

Name: ………………………………………………………………………………………

Email: ………………………………………………………………………………………

Elaine will email you in 6 weeks time to find out how you've been getting on.

Figure 20: The Change Promise cards

7.6.8 The change promises: follow up

Participants had been told that I would email them 6 weeks after the workshop, to find out how they were getting on. I had gained an amendment to my ethical approval to be able to do this.

I conducted a brief thematic analysis (Braune & Clarke, 2006) of the ideas people had for the changes that they wanted to make, which showed five predominant themes:

- Increasing own knowledge and learning. Usually expressed as doing more reading and research, better familiarisation with legislation.
- Making personal changes. This included things such as 'the way I think about self-neglect', but also not being afraid to speak out, being aware of becoming desensitised, and considering one's own values, and 'how I could do more with difficult to engage service users.'

- Helping others increase their knowledge. This included sharing knowledge at team meetings, but also ‘educating partner agencies about what my agency CAN DO’.
- Better joint working. This included working more closely with other agencies, calling more MDT meetings and promoting joint assessments.
- Changes to mental capacity assessments. This included more thorough assessments, better recording and shared decision-making. Changes relating to MCA assessments were the biggest group of changes that participants identified they wanted to make, which could indicate that although the workshop had not been specifically about the MCA, participants had nonetheless learned from others in their discussions. However, it also affirmed that individual concerns about the operation of the MCA which emerged from the group interviews, continued to be very much of an issue.

These responses were extremely interesting in how they reflected the wider ‘Headlines’ that had originally been identified, and how those Headline changes could relate to individual practice. Six weeks later, everyone who had completed a card received the following email from me,

Hello *(name inserted)*

I hope you are well. Back in May, you attended a workshop about self-neglect and multi-agency working that I ran. At the workshop, you completed a *‘Making a change in practice’* card, where you wrote down one thing in your practice that you wanted to change as a result of attending the workshop, and I promised that I’d follow up with you in six weeks’ time to find out how you were getting on.

You wrote that the change you aimed to make was to [*Participant’s idea for change inserted*]
It’s now six weeks later, so I’m emailing to ask you three questions:

1. How successful have you been in making (or starting to make) the change that you wanted?
2. What have you done?
3. If you’ve run into any difficulties, what are they?

Do email me back and let me know how you have been getting on– I’d be really interested to find out! Just fill in your answers to the questions above and send them back to me.

I look forward to finding out how you’ve been progressing! Best wishes

Elaine

Figure 21: Follow-up email to participants

Around one quarter of original participants responded to the emails. Some of the individual replies indicated that real and meaningful changes had been made on an individual level to practice. The following example concerned the original ‘change promise’ of appointing a care co-ordinator in the participant’s particular workplace setting;

> 1. *How successful have you been in making (or starting to make) the change that you wanted?*
>   – Yes I have started the process and a care coordinator is now identified.
>
> 2. *What have you done?*
>   - At each triage we identify who would be the best person to lead on the referral. We currently have a board in our office, the patient is placed on the board until the identified professional can assess.
>
> 3. *If you’ve run into any difficulties, what are they?*
>   – This process seems to be working well at this time (Community Nurse)

Where things had not gone so well could be because of lack of resources or lack of time. However, this did not mean people were discouraged. One participant wrote that her situation was,

> A sorry state of affairs that I am addressing! (GP)

Another participant wrote that they would,

> Need longer term input to make change here. But it was reassuring to hear [at the workshop] that everyone wants to make a positive change and that it will continue to be a topic with grey areas. (Housing manager)

7.7 Post workshop reflection

After each workshop, I reflected extensively on how they had gone, and what changes could be made to subsequent iterations of the workshops. All of the participants had completed feedback forms anonymously, and it was very useful to use the feedback to assist my reflections. It was overwhelmingly clear from the feedback that the value of the workshops for practitioners lay in,

> Working in partnership with a variety of agencies all coming together linked with a shared concern (Participant feedback)

The opportunity to come together and share experiences was clearly highly valued, in and of itself,

> I really enjoyed the content, company, and thought provoking discussions (Participant feedback)

However, what also emerged from the feedback was the sense that participants had found the idea of a participatory workshop, rather than more formal training, did not fully meet their expectations. Whilst one participant ‘loved the discussions on our table, whole MDT involved’, another felt that;

> I would have liked to have looked at some previous evidence based practice or looked at some serious case reviews rather than just the group’s personal opinions. (Participant feedback)

Despite my being explicit in the information about the workshops that this was not a conventional training course, several participants stated in their feedback that they would have liked the inclusion of things more associated with training, such as ‘policies and procedures relating to local area’; ‘more information on case law’; ‘more case studies’.

I mentioned above my concern that over-emphasis on the MCA would distort the purpose of the participatory workshops, and this was borne out by some of the feedback. Participants fed back that they would have like more input about the MCA in relation to people who self-neglected, and some responses revealed a clear training need in this area;

> [I would have liked] to look at capacity assessment in certain areas, a good capacity assessment/bad assessment. What do you do if their capacity is deemed as having no capacity, what do you do with it? (Participant feedback).

As mentioned at the start of this chapter, one of Allport’s (1954) pre-conditions for successfully bringing a group together to reduce conflict was that group members must be of equal status. Whilst status differences were not obvious in the group interactions that I observed, they were reflected in the feedback. One participant wrote honestly that,

> I wasn’t as knowledgeable as some people and there was some ‘jargon’ and areas I couldn’t contribute to. (Participant feedback)

Meanwhile, a participant who clearly saw themselves as one of the knowledgeable ones wrote that,

> A lot of information was aimed at staff with less experience in dealing with cases. (Participant feedback)

However, this participant also wrote that,

> The workshop was perhaps more useful for the research project than from a teaching perspective.

This is a very interesting comment in light of the fact that the workshops were not ever intended to be teaching sessions, and I had striven hard to avoid this. It is hard to avoid the conclusion that the practitioners involved in these workshops were seeking training and teaching. These are the things that will help them when re-registration comes around, and where they perceive the value to themselves to lie. In adult learning terms, they are surface learners (Marton & Saljo, 1976). Although many participants were able to engage with the participatory nature of the workshops, and understood that they were engaged in a mutual endeavour to bring about change (Noga et al, 2016), that was not true of all of them. As Noga et al (2016) note;

> Since action research is aimed at change, it can be perceived as threatening for individuals and organisations and the question 'how could things be done differently' can be extremely daunting. (p11)

7.8 Conclusion

This chapter has described a cycle of AR, which followed on from the problem-sensing phase (Hart & Bond, 1995). However, within this overarching cycle, there were four distinct 'plan-act-observe-reflect' cycles represented by each workshop. Four multi-agency workshops were planned and carried out, involving in excess of 120 participants from all of the different agencies involved in working with people who self-neglect. I have described 'action research in the moment' (Mackewn, 2008, p615) as I facilitated the workshops. I then discussed my reflections after the workshops, and how these were informed by feedback from participants. In the next chapter, I will discuss the findings from both the initial diagnostic stage (the interviews), and the subsequent action phase (the workshops).

Chapter 8: Discussion, analysis and interpretation of findings

8.1 Introduction

The overall aim of my research was to explore the understandings of self-neglect and multi-agency working espoused by the professionals from different disciplines who work together to safeguard self-neglecting adults. I hoped to gain insights into how practitioners perceived the effectiveness of multi-agency working in this complex and demanding area of work. By my using an action research approach, my research aimed to build an understanding of how multi-agency working in self-neglect cases could be successfully developed, at a local level, to improve outcomes for service users. Because in AR the intention to intervene is explicit (Sandars & Waterman, 2005), I framed my overall research question as,

> How can professionals improve the way they work together to promote the welfare of service users who self-neglect?

There were four research objectives within this;

1. What are professional's roles and responsibilities in relation to self-neglect cases and how do the different professionals contribute to a joint understanding?
2. Do professionals share a language around self-neglect?
3. How do various professionals reach consensus in relation to self-neglect and how may different professional values conflict with each other?
4. What do professionals consider as important in achieving successful multi-agency working?

Action research is an ongoing process (Stringer, 2014), where 'new realities emerge that extend the process of enquiry' (Gray, 2014, p338). My research is ongoing, but what follows is a discussion and analysis of the first complete cycle of the research.

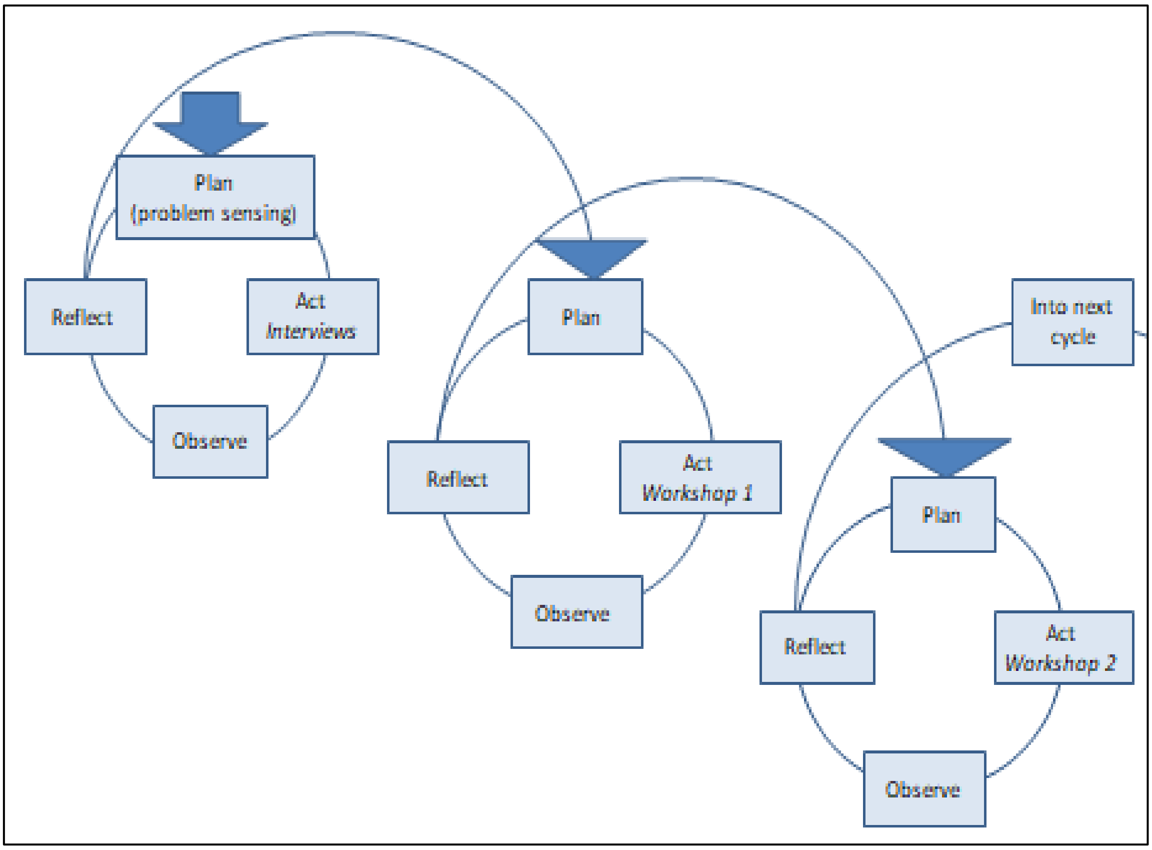


Figure 22: The AR process in relation to this research

In this discussion I will explore the first three research objectives in relation to the findings from the problem-sensing phase of this research, the group and individual interviews detailed in Chapter 6. I will then consider the fourth objective, ‘what do professionals consider as important in achieving successful multi-agency working?’ in relation to the multi-agency workshops discussed in Chapter 7. I will then move on to examine the overall context in which my research took place and the impact of this on the research.

8.2 Objective 1: What are professional’s roles and responsibilities in relation to self-neglect cases and how do the different professionals contribute to a joint understanding?

During this I study found considerable uncertainty in participants understandings of each other’s roles and responsibilities in general and specifically in relation to self-neglect. This is in line with other findings (Philipowsky, 2018; Miller & Mangan, 2016; McCreadie et al, 2008). Lauder et al (2005a) highlighted more than 10 years ago that a much clearer understanding of each other's roles was necessary to ensure the success of multi-agency working, yet Miller & Mangan (2016) note that despite decades of collaborative working, such uncertainty persists. Many of the participants in the study will have learned about multi-agency working as part of their pre-qualification courses (MacDonald et al, 2010), and participated in multi-agency training, so it is hard to see why this should be the case. Recent examinations of SAR's reports (Preston-Shoot, 2018) show that failure of agencies to clarify their roles and responsibilities have contributed to poor outcomes for service users who self-neglect, so it is a key issue.

Participants presented a lack of understanding of job roles and responsibilities of others in one of two ways. These were either that participants felt that other agencies did not understand *their* role and responsibilities, or that *they* did not understand the roles and responsibilities of other agencies (Chapter 6, section 6.4.7). McCreadie (2008) found that respondents in her study tended to believe that they were clear about their own roles and responsibilities but that others misunderstood them, and this held true here. Staff expressed indignation and frustration where they felt other agencies did not understand their role. This was particularly acute where things such as professional entry requirements or employment status had changed in recent years for these professionals. Thus, for example, one Housing Officer, educated to degree level and no longer employed by the local authority, felt he was just seen by other agencies as the 'rent man'. Environmental Health Officers felt they were seen as 'the clearance team', qualified mental health professionals as 'support workers', paramedics as 'ambulance drivers' and so on. They were irritated that other professionals had simply not kept up to date with changes in their roles. As practitioners striving to assert their professional identity and status in the multi-professional arena, this sense of being seen as lower status than they saw themselves was described as impacting on the practitioner very personally, 'it's as if you're being negated' (Social worker). If other people do not understand what a person does, it seems to imply to the person involved that their role is somehow not important enough to be understood by others. This was the source of immense frustration for those practitioners. In some cases, efforts were actively made to help other agencies understand what their agency did, but these were not always successful,

> We do raise the awareness of what we do, but there are, even now, I still go to partnership meetings and they go 'oh, I didn't know you did that, I thought you just put fires out (Fire services).

One problem signalled to me by several agencies in relation to role understanding between professionals working with self-neglect, predominantly social services, was the misunderstanding of their specific legal remit, for example, the belief by others that they had ‘the powers’ to remove people forcibly from their homes or ‘make’ them clean up.

When participants from an agency did not understand the role of other agencies, this was generally blamed upon the other agencies. It was seen as ‘their fault’ that they did not promote their service well enough, or that they kept what they did shrouded in mystery. Social workers seemed to fare particularly badly in this respect, with one occupational therapist only having a ‘vague idea’ of what they did, whilst a police officer felt ‘they don't seem to do anything much’. Cameron et al (2014b) similarly identify a significant level of scepticism and protectionism amongst staff on integrated teams. Interestingly though, there was sympathy where it was perceived that other agencies had experienced serious financial cuts and re-organisation and thus could not provide the service they once did. As with Noga et al’s (2016) findings, instead of challenging such situations, participants seemed simply to accept them.

8.2.1 Understandings of roles and responsibilities in relation to the MCA 2005

A common factor for all of the participants in this study was the operationalisation of the MCA 2005 and the difficulties this entailed regarding who was responsible for what (Braye et al, 2013). In this research, this is where the multi-agency perspective was invaluable to me, as much of the research around the application of the MCA in practice has focussed on a handful of professions. What I found emerged was real confusion about which agencies should carry out MCA assessments (Hinsliff-Smith et al, 2017; Ratcliff & Chapman, 2016), and an elaborate picture emerged of participants who opined that they did not, should not, could not, or would not carry out assessments (chapter 6, section 6.5.3). It is important to note that the Act itself does not specifically include or exclude any professional from carrying out the assessment. The Act was designed to move away from a need for 'expert' judgement, as required, for example, by the Mental Health Act 1983, to mean that a wide range of people could be involved in the assessment of mental capacity. The current advice from the Social Care Institute for Excellence (2019, np) states that, **'**Anyone caring for or supporting a person who may lack capacity could be involved in assessing capacity'. The SCIE is clear that 'good professional training is key' (ibid) rather than reliance on experts.

Generally, it is the person who is proposing to take the step in question (for which a choice needs to be made) who should carry out the assessment, (interpreted by one participant, an occupational therapist, as 'anyone can do it apparently'). This will depend on the decision to be made, and the practitioner with the best knowledge of the person being assessed,

> it is frequently the case that professionals or others who know the person better, and in particular who have seen the person over time, will be able to do a more robust capacity assessment than a person (of whatever discipline) 'parachuted' in for a snapshot assessment (Ruck Keene et al, 2016).

Two key agencies reported being frequently 'parachuted in' to do assessments, paramedics and social workers. I found that for social workers, although this was an intense frustration because they often did not know the person they were being asked to assess, they were generally clear about the requirements of the MCA 2005, and not under critical time pressures. For paramedics, in emergencies, I found it was something that made them feel very vulnerable, particularly as they perceived that a wrong decision could lead to an assault charge (Chapter 6, section 6.5.1). Jones (2014, p180) notes that, 'Police officers and paramedics often share constant challenges in real time situations relating to consent and capacity'. However, the sharing of challenges was not evident here, as the police officers who participated in my study were clear that where capacity was an issue, they would usually ask paramedics to carry out the assessment.

Participants from several agencies stated categorically that they did not carry out MCA assessments, a position entirely without justification under the current legal framework in England. These directly included the police, Fire and Rescue services, Housing, Community Mental Health Nurses, Community Nurses and Environmental Health, and anecdotally, GPs. Reasons given for this were predominantly that they were not paid enough to do them, they were not trained or qualified to do them, they were not 'the experts' (Community Nurses) or did not have 'a professional background' (Environmental Health), or simple unwillingness. As one social worker noted, 'no other agency particularly wants to do capacity assessments'.

This presented a contradiction. Although participants felt that others did not understand what they did in their jobs, as previously discussed, and thus did not accord them the respect they felt they deserved, they did not choose to enhance their professional status by seeking to be equipped to carry out capacity assessments. To consider doing this was described as 'overstepping' by one participant, working in Housing. They were instead content to criticise how assessments were done and the decisions that were reached by others (Clerk et al, 2018). There was not only a high level of criticism of assessment outcomes (which will be discussed further later in this chapter), but much discontent expressed about not being asked to contribute to assessment, and not being asked for opinions particularly when they knew the service user well. No participants were of the view that they would offer information spontaneously, all stated rather that they were waiting to be asked, but then were irritated when they were not. These seem perverse and self-defeating stances, which ultimately impact negatively on the service user and which are a distortion of the original purpose of the Act (House of Lords, 2014)

It was clear that lack of training was a key issue, and this was remarkable given the length of time the Act has been in force (Alonzi et al, 2009) (Chapter 6, section 6.4.14). Many participants reported having no training at all, and the discussions left me convinced that there was a high level of misinformation about the Act. However, both Rogers & Bright (2019) and Willner et al (2013) found that the benefits of training in the MCA 2005 may be limited. Training appears to raise awareness about the MCA 2005, but does not seem to make practitioners any more able to apply it practically. Braye et al (2013) reported a similar finding.

The role of mental health services in working with people who self-neglected was one that many groups of participants found hard to understand, particularly the refusal of community mental health nurses (CMHN's) to carry out assessments of capacity,

> They'll say, oh we can't do capacity assessments, which I found quite astounding. The community mental health team in this area, they can't do capacity assessments (Social Worker).

In fact, carrying out MCA assessment is not necessarily a part of a CMHN's role, as they are specialists in mental health, not mental capacity. However, this conflation of mental health and mental capacity by participants is not unusual (Rogers & Bright, 2019). It was also reported that mental health services would not become involved with people who hoarded, who had substance misuse problems, or who had difficulty keeping appointments. I gained a strong sense from participants that mental health services should assume responsibility for working with people who self-neglected, but as research shows that a substantial number of people who self-neglect do not have a mental health diagnosis (Lauder et al, 2005a), it is hard to justify this. All of the points raised by participants in relation to who should carry out assessments align with Jayes et al (2019) who note that,

> Decisions about which disciplines take responsibility for individual assessments appear to be influenced by factors relating to skill mix, perceptions about discipline-specific roles and professional hierarchy (p9).

Therefore, to summarise, in this research I found poor understanding of job roles and responsibilities in relation to multi-agency working with people who self-neglect, coalescing particularly around understandings of roles and responsibilities in relation to the MCA 2005.

8.3 Objective 2: Do professionals share a language around self-neglect?

Issues relating to communication emerged as being highly significant for practitioners in both the interview and workshop phases in my research. I identified seven dimensions of problematic communication, through thematic analysis of the data from both phases, as previously described. These were:

Table 10: Seven dimensions of problematic communication

	Seven dimensions of problematic communication
1	The language practitioners use in talking about self-neglect
2	How individuals communicate – face to face, phone, email
3	How their organisations communicate
4	Where communication takes place
5	Who practitioners communicate with
6	What can be communicated – information sharing
7	When communication is happening – timely communication

In this section I will focus on the first dimension of communication identified, the language used by practitioners to talk about self-neglect. I will consider dimensions 2-7 later in this chapter.

Post-structuralist theory drew attention to the way in which language constructs reality, and this is particularly relevant in a field like self-neglect, dominated by an unstable frame of references. (Burr, 1995). However, these constructs will be continually changing, because language is ‘a site of variability, disagreement and conflict' (p41), which can be manipulated or challenged. Massey (2010) highlights the way in which vocabulary has been pivotal in establishing and embedding neoliberal thinking. Green (2014, p*ix*) describes the development of a form of 'newspeak', *pace* George Orwell, couched in 'mellifluous, calming phrases, designed to allay suspicions, modify facts and divert one's attention from difficulties'. The very fact that the issue under discussion here is called 'self-neglect' rather than 'societal neglect' allows the wholesale diversion of attention from the wider economic and political picture to focus on individual culpability. Participants in the study saw self-neglect as 'new', 'modern', 'suddenly recognised', 'flagged up', and they were accordingly learning to use the new language of this area of work. However, three areas emerged as hindering the development of a shared language,

- the paucity of language available to participants to describe self-neglect,
- a discomfort with the language that was available to them,
- the adoption and development of professional jargon and euphemisms particularly surrounding the concept of 'lifestyle choice'.

I will discuss these points in the following section.

8.3.1 The paucity of shared language: Talking about 'squalor'

Communication and the development of a shared language is crucial to effective multi-agency working (Suter et al, 2009; Verhaegh et al, 2017) and this may be particularly true in newly developing areas of work, such as self-neglect. An example is the use of the word 'squalor'. In McDermott's 2008 study of Australian practitioners, she found that though the term 'self-neglect' was not universally used, all of her participants routinely used the term 'squalor' to distinguish those homes which were extremely unclean from those which were simply untidy. McDermott (2008) argues that the distinction to be made between the terms 'self-neglect' and 'squalor' is important because this will have an impact upon professional judgements of risk. The term 'squalor' is frequently and routinely used in the literature on self-neglect, to describe extreme environmental uncleanliness, notably in Australia (e.g. Snowdon & Halliday, 2012;

Gleason et al, 2015), and the USA (e.g. Rasmussen et al, 2014). The constituents of squalor are poorly defined (Rasmussen et al, 2014), though Snowdon & Halliday (2012) go so far as to identify six sub-types of squalor (see Chapter 2, section 2.2).

I found very little use of the word 'squalor' by participants in the more than 30 interviews that I have completed. To set it in context, the phrase 'self-neglect' appears more than a thousand times in my interview transcripts, whereas the word 'squalor is used spontaneously only nine times by my participants. In the rare instances where it was used, the word was usually qualified. One participant, from Fire services, highlighted that it was not a word that they were using as part of their natural vocabulary, but rather a special category of word, describing how a person 'lived in what *we would call* squalor' (my italics), rather than simply stating they 'lived in squalor'. Another participant used the term to demonstrated how far-fetched the judgements of others might be,

> And some people's ideas of squalor in their lives mightn't be as bad as what they perceive it to be, because we've actually seen other houses or other people who live in worse conditions (Environmental Health).

'Squalor' is undoubtedly a word to which a stigma is attached and it is not a neutral word (Lauder, 1999b). Although identified more than 75 years ago in the Beveridge Report (1942) as one of the five 'giant evils' (p41), the term seems to have faded from use, perhaps in the belief that the welfare state has somehow eradicated it. It is possible that practitioners feel they are being judgemental if they use the word. However, this reluctance may suggest that if practitioners are not using the term 'squalor' it potentially limits their vocabulary to describe adequately situations of extreme environmental neglect. Thus there is a risk that the severity of extreme cases is understated, simply because of the paucity of vocabulary to adequately describe them (McDermott, 2010), or become 'woolly' (Aylett, 2016, p35). This resonates with Doron's (2013) study of responses to self-neglect where he notes that participants who worked with self-neglect seemed to lack the words they needed to describe what they were seeing.

8.3.2 A discomfort with language: The absence of smell

Synnott (1991) highlights the importance of smell in the moral construction of self and others. Friedman (2016) takes this further in suggesting that sensory perception is an important part of social construction. Both Synnott (1991) and Friedman (2016) argue that Western society is ocularcentric, in that visual information is privileged over information from the other senses, particularly the olfactory sense, yet odour is an important component of how we construct reality and the moral judgements we make (Synnott, 1991). Acknowledging and referencing odour as, for example, part of a referral to another agency or an assessment can be very important in working with self-neglect. This may be both in terms of what the smell may indicate about the condition of the person and their environment, such as the smell of gas, or the smell of rotting food, and in terms of how smell may make the practitioner feel,

> How should a professional deal with squalor that smells so strongly that he or she feels sick upon entering the residence? (McDermott, 2011, p55)

It was noticeable in this study that participants spoke vividly about how environments or people looked, and were clearly very visually observant, but they very rarely spoke about odour, even though this would be immediately obvious and important in most self-neglect situations, where ‘the smell is coming through the letterbox’ (Environmental Health). One practitioner, a domiciliary care worker, who did speak of it, demonstrates this. It was clear that odour was a key part of her assessment of the service user’s decline,

> I hadn’t seen her for weeks. I noticed straight away she smelled. I mean, she smelled of self-neglect really bad. You can smell her as soon as you walk in.

This sensory omission in the discussion and assessment of working with people who self-neglect, whether through embarrassment or discomfort, would seem to bear out Classen et al’s (1994, p4) assertion that ‘Smell has been silenced in modernity’. Allan & Burridge (2006) suggest that words associated with bodily effluvia are taboo, and use of them can lead to disapproval and ostracisation. Yet if it is omitted from practitioners shared language, it becomes a dimension of their assessment of situations that cannot be named and therefore is missing (Horwath, 2007).

8.3.3 The adoption and development of professional jargon and euphemisms

In terms of a shared language between practitioners who were working in the newly emerging and legally mandated area of self-neglect, I have found some evidence of the development of a shared language, as one participant said, ‘we’ve got a basis for talking in a common language that’s the thing now’ (Housing Officer). As Waring et al (2018) notes, this is important to facilitate information sharing, particularly in emergencies. However, in my study this appeared to be dominated by jargon and euphemism (Allan & Burridge, 2006).

Using jargon, which Hudson (1978, p2) defines as ‘the specialised technical language of different occupations and interests’, is not, he argues, inherently wrong, as it can provide professional cohesion. However, Hudson notes that it may mitigate against good communication between different groups. Jargon could also be part of the inclusive language needed to enhance multi-agency communication, though conversely its exclusivity could impede communication (Sheehan et al, 2007). Participants in my study provided many examples of how what one participant, a Housing Officer, described as ‘the fancy terms and jargon’, could be used strategically by practitioners wanting to advantage themselves and their agency (Mason et al, 2017) (Chapter 6, section 6.7). Jargon could either be used to confuse other agencies working with self-neglect, as in ‘they won’t know what I mean, they’ll just stop asking’ (Housing Officer), or alternatively, to ‘make them sit up and listen’ (Social Worker). Jargon was also treated with cynicism, identified by one group of participants as being used to promote joint working by their employers, along with ‘wonderful straplines and wonderful presentations’ (Physiotherapist), but in reality being ‘the Emperor’s new clothes’ (Community Nurse).

8.3.4 When is a lifestyle choice not a lifestyle choice?

An example of euphemisation (Bourdieu, 1977) in this research was the frequent use of the term ‘lifestyle choice’ (discussed in chapter 2), to justify or excuse inaction by agencies into a self-neglecting person’s life,

> I’ve had it where they’ve said it’s lifestyle choice, it’s lifestyle choice and that’s all I’ve had (Housing Officer).

The idea of lifestyle can be defined as ‘leading life in sympathy with a plan, principle or ethic’ (Featherstone, 2015, p383), and is now generally used to mean a person’s approach to life, particularly through their choices of consumption (ibid). Its use, Mayes (2015) argues, masks the neoliberal shift from socialised to individual welfare. Ash (2014) argues that the ‘lifeless jabbering of the choice refrain’ (p23) is a problematic concept in public policy, whereby the fetishisation of the ‘warm word’ (ibid) of choice not only permits inaction by professionals, but may put vulnerable people at greater risk (Pritchard, 2001; Flynn et al, 2003; Butler & Drakeford, 2005; Keywood, 2010; Massey, 2013; Scourfield, 2010; Ash, 2014).

I have found two opposing responses to the phrase employed by participants in this research, uncritical acceptance, and critical rejection (Chapter 6, section 6.3.10). Social workers in general seemed comfortable with the term ‘lifestyle choice’, even though, as in this example, they felt they were putting themselves in opposition to ‘society’ by regarding a state of neglect as a choice,

> R1: We have some people that make lifestyle choices that others, maybe society, would state that they're in a state of neglect, but that's the way they're choosing to live
>
> R2: They're happy
>
> R1: Happy to live in that way. (Social Workers)

This attitude is possibly a reflection that they may have greater awareness of the English legal framework in respect of human rights than other practitioners may. It may also be that their knowledge that they have limited powers to intervene where a person has mental capacity means they have a more laissez faire attitude if someone seems ‘happy’. This is commensurate with the findings of Harbison et al (2004), that there is higher professional tolerance of self-neglect when it is seen as a lifestyle choice than when it is seen as stemming from physical or mental impairment. However, such an attitude also permits the avoidance of responsibility (House of Lords, 2014), as noted above. This is encapsulated in the case of ‘squalor’, previously discussed, which appears to have undergone a transformation from a ‘giant evil’ (Beveridge, 1942) to a ‘lifestyle choice’.

In contrast, many other participants from different agencies were very unhappy with the term, and the cognitive dissonance that it entailed. They argued that it was a phrase that was repeatedly used but meant nothing, a ‘funny term’ (Homelessness worker). One community nurse felt that the person’s illness and frailty impeded the idea of choice, ‘if he was fit and well, would he choose to starve himself as he’s doing now?’, another that self-neglect ‘creeps up on you’, and that it could not be considered an active choice. It was seen as an issue of professional pride and esteem that some professions, ‘similar to ours who would see behind that, would see beyond it’ (CMHN). But the really difficult thing, as McDermott (2010) also found, was to try to separate out one’s own values from one’s professional judgements,

> And it is so hard when their lifestyle choices are such an extreme to what you know … and however open-minded you can be, you know, you don’t feel is acceptable. Because you do get to that situation where you think this is just not an acceptable way of living and I know that’s my viewpoint but it’s just not acceptable. (Social worker)

Perhaps unsurprisingly, these differing perspectives, rooted in personal uncertainty, led to conflict, which will be discussed further in relation to the third research objective.

8.4 Objective 3: How do various professionals reach consensus in relation to self-neglect and how may different professional values conflict with each other?

In Chapter 3 I discussed some of the many studies which have looked at conflict in multi-agency teams (e.g. Brown et al, 2011; Almost et al, 2016), and its apparent inevitability in such settings (Watts & Jones, 2000; Kim et al, 2006). Therefore, it was not perhaps surprising that in conducting this study I should have found high levels of inter-agency conflict in the complex area of working with people who self-neglected (Chapter 6, section 6.4.19). Brown et al, (2011) suggest that where a patient represents a ‘wicked’ problem (a patient with a complex set of symptoms or complex biopsychosocial issues), this may necessitate multiple interventions, which can create conflict if the professionals involved, do not agree. As highlighted in Chapter 3, studies of interventions to manage or minimise conflict are lacking (Almost et al, 2016), as are studies which look at interventions to develop practitioners problem solving skills (Sexton & Orchard, 2016).

In Chapter 3, I considered Matland's (1995) ambiguity-conflict model of policy implementation. McCreadie et al (2008) propose that safeguarding policy is of the high ambiguity/low conflict type of policy implementation. In Matland's terms, a high ambiguity policy should limit conflict, as there is essentially more room for manoeuvre by actors. However, McCreadie et al (2008) question whether it is possible for high ambiguity to exist without causing conflict, even where there is room for local flexibilities in implementation (as with the Care Act 2014, discussed in Chapter 1). In the context of my study, the picture that emerged in relation to practitioners' safeguarding people who self-neglected and implementing the MCA, was one of high ambiguity, caused by highly permissive but poor policy guidance in the Care Act (Fitzgerald, 2016) and widely varying interpretation of the MCA. As one social worker said, 'I think we're a little bit unclear because we haven't got guidance yet. Our policy was very descriptive'.

However, the picture also emerged in my study of a high conflict situation, couched by participants in many instances in the metaphor of warfare (Allan & Burridge, 2006), which Matland (1995) argues, leads to merely symbolic interpretation of policy. In this high ambiguity/high conflict scenario, agencies can put limits on policy implementation, even when they cannot determine its content. The previously mentioned disinclination of agencies in this study to undertake MCA assessments could be seen as an example of this. Matland (1995) notes that symbolic policy interpretation is likely to be important for the professions, whose professional training has provided them with strong norms and their own ways of operating

(Stuart, 2012). Where there is ambiguity, these groups will step in with proposals rooted in their own professions, as with this Housing Officer,

> I don't think the other agencies would be so equipped to look at the way we've been trained, you know, looking at the person and their life, you know.

Kim et al (2016) suggest that conflict can be task-based (such as implementation of policy) or relationship-based (different norms and values). However, in my study, the two appeared to be strongly linked, where the task of working with people who self-neglect and implementing policy, could be viewed very differently according to the professionals own values and ethical perspective (McDermott, 2011; Braye et al, 2014). Clerk et al (2018) argue that lack of consensus is the result of two different ethical perspectives, the consequentialist, or making a choice will maximise good consequences (the 'happy' self-neglecter discussed in relation to lifestyle choice for example) and the deontological, or what one ought to do in relation to duty or obligation. This latter perspective was found by McKenzie, Metheson *et al*. (2001) to be significantly more likely to be emphasised by health staff. However, that might be considered an over-simplification, and it was summarised best by a social worker in this study, who said that if a person was self-neglecting, 'I would do my best to find out the underlying reason and try and point them in the right direction and I feel that is my duty.'

In this study, a complex picture emerged of the genesis of conflict, which involved factors little discussed in the literature, namely how individual fears may drive conflict, and how practitioners develop strategies to manage conflict. Figure 26 below summarises this.

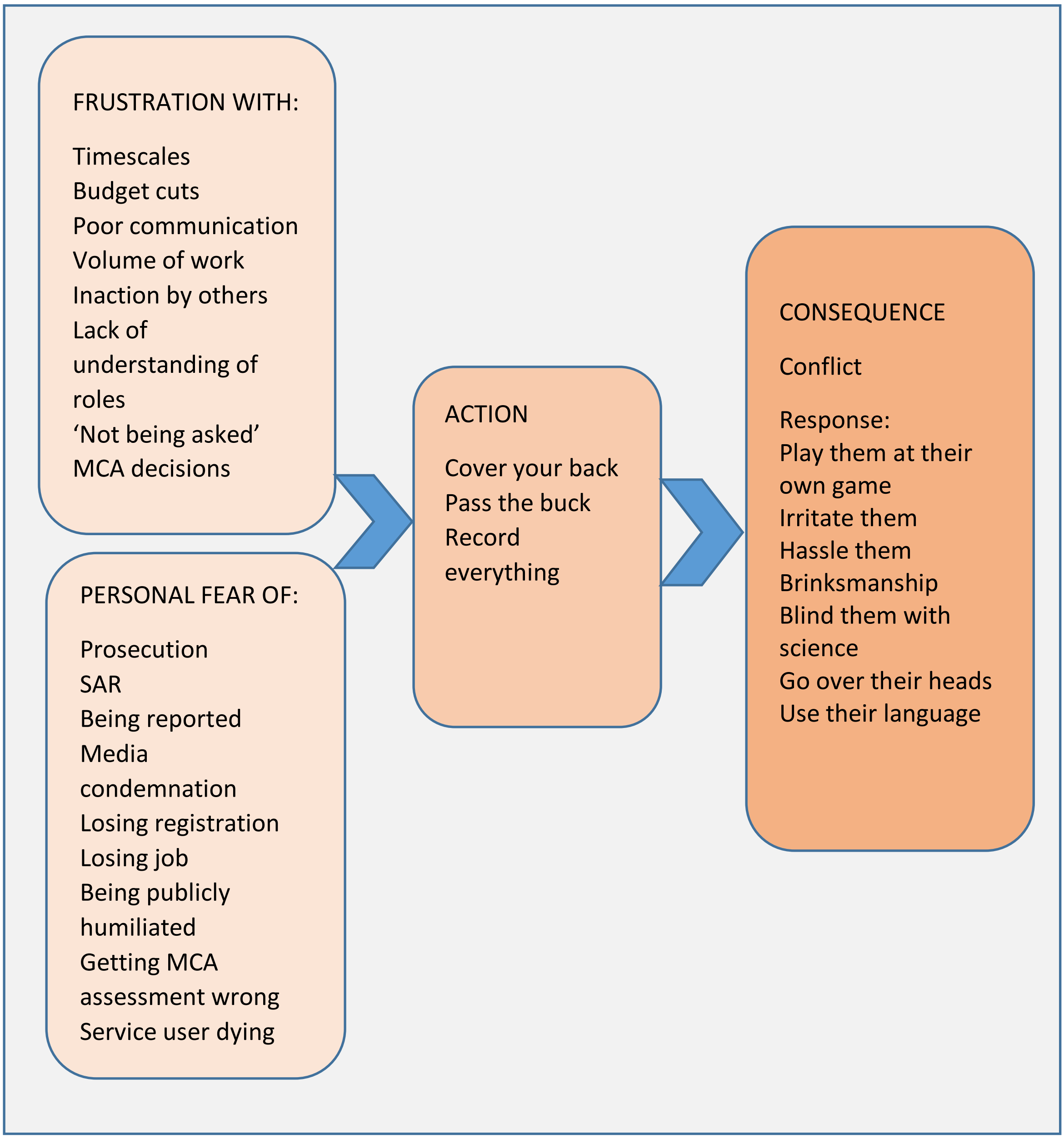


Figure 23: The development of and responses to, conflict in multi-agency working

Many studies have shown that barriers to multi-agency working exist and what these barriers are (Brown et al, 2011; Auschra, 2018). Many of them are rooted in the systems, processes and cultures of different agencies, which clash with one another (Mackie & Darvill, 2016). Examples of these from this study were different response times and inflexible IT systems (Chapter 6, section 6.2.2). What studies often fail to describe is the impact that these barriers have on practitioners and how the actions they then take can trigger and fuel conflict. They are generally barriers against which individual workers are relatively powerless, but that does not mean that they are simply accepted with equanimity.

Conducting this study gave me a sense of the frustration practitioners experience in their day-to-day work, with the barriers to multi-agency working, which they encounter, that are associated with the different perceptions of risk held by practitioners. Barriers that were highlighted in this study are included in the box above. These were repeatedly described by participants as, for example, 'sheer frustration' (Housing Officer), 'frustration for everybody' (Community Nurses), 'frustrating all the time' (Police).

However, practitioners do not simply experience frustration, they also experience fear (Chapter 6, section 6.5.1). Although there is little in the literature addressing this from a multi-agency perspective, Smith et al's (2017) studies of workers in child protection identified a sense of fear, 'the precariarity induced by neo-liberalism whereby workers are to be kept on their toes and held to account for anything that might go wrong' (p980). Howarth's study (2007), also of child protection, identified practitioner fear of making the wrong decision. This has strong resonance with practitioners from many different agencies in this study who expressed fears associated with something 'going wrong' with a self-neglecting service user, which was outside of their control,

> Knowing also that if it all goes wrong that we'll find ourselves under the microscope. Why didn't you do this, why didn't you do that, justify that you took appropriate action? (Community Nurse)

Stanford's (2010) study identified three types of fear expressed by practitioners; the negative reactions of colleagues and other professionals; physical violence from service users; and causing harm to service users. The participants in this study expressed rather different fears (See Figure 26, above). Fear of physical violence from service users was not expressed at all. Causing harm to service users was expressed in terms of fear that the service user might die because of an omission on the practitioner's behalf. However, this was not a commonly expressed fear, perhaps because of people routinely working with older service users or those with chronic or multiple health problems, dealing with death is common. Negative reactions could be seen to be things such as being publicly humiliated (‘named and shamed’), or being ‘reported’. However, the fears which were repeatedly expressed to me, and which Stanford’s (2010) study does not mention were those which would directly impact upon the practitioner themselves, and which were more than fearing a negative reaction. They were the loss of job, professional registration, even home, mortgage and family (Abramovitz & Zelnick, 2015). They were prosecution, imprisonment, in short, catastrophic, life-changing events. Lazaratto (2009) describes the anxiety, insecurity and increasing precariarity engendered in workers as the ‘micro-politics of little fears’ (2009, p120). However, what my participants were expressing were very big fears indeed. Combined with the frustration they described, there was thus a strong impetus to take action (see Figure 26), action to ‘cover your back’ (Housing Officer), ‘pass the buck’ (Fire Services), ‘record everything’ (Community Nurse).

8.4.1 Defensive practice

The notion of covering one’s back as a priority correlates with the findings of both Noga et al (2016) and McCreadie et al, 2008). The latter also note the ‘diligent paperwork procedures’ (2008, p255) used to divert blame and provide defence. However, it is important to note that participants in my study, whilst adopting the required tactics, were highly critical of them, seeing them as incompatible with good patient/service user care (chapter 6, section 6.4.5). They were also critical of their own management in many cases, for requiring this defensive practice,

> We have to produce a raft of care plans for them and non-engagement letters have to be put in place and everything because [our employers] want protection if anything happens (Community Nurse)

Similarly, the idea of agencies ‘passing the buck’ (Shoesmith, 2016) correlates with Braye et al’s (2014) identification of ‘threshold bouncing and a silo approach’ (p49), in self-neglect. This is where a person’s needs are not considered holistically because all agencies are anxious to avoid taking responsibility.

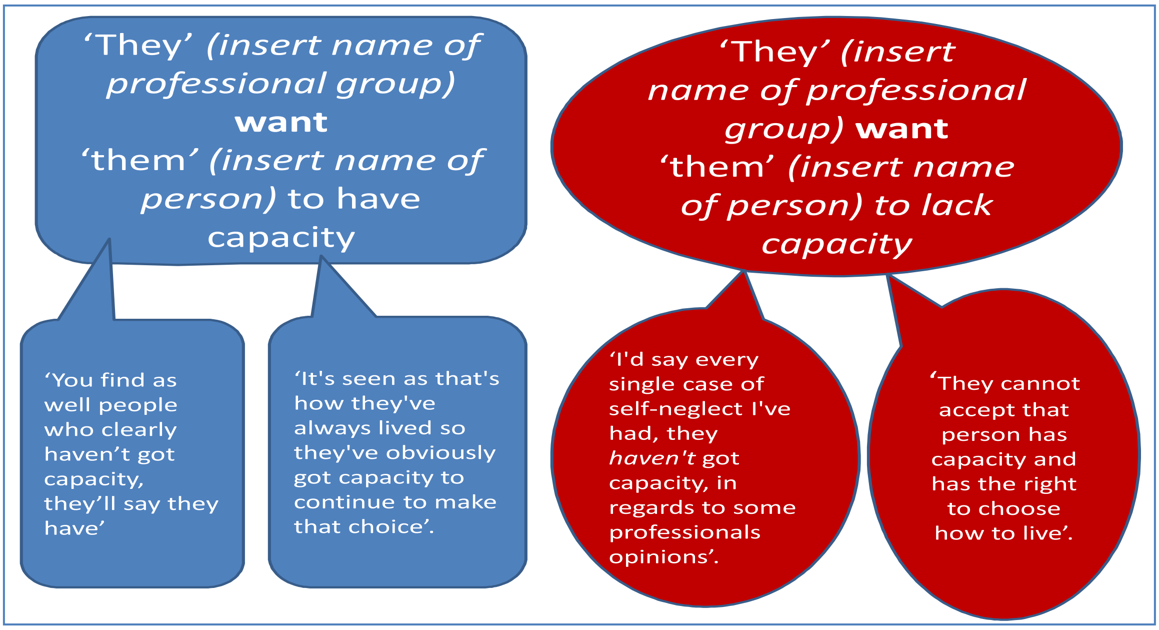
8.4.2 The Mental Capacity Act as a source of conflict

As previously discussed, the issue of who should carry out a capacity assessment was one that caused conflict between agencies. I recorded participants expressing a fear of getting an assessment wrong (Chapter 6, section 6.4.13). In some cases, medical terminology was used to describe this as process of ‘misdiagnosing’. They struggled with the binary nature of capacity decisions,

> It gets in the way, because then no, MCA says they've got the capacity to do that, and you just think, that's very sad (A&E Consultant).

and with the sense of de-professionalisation engendered by the MCA, which appeared to leave no room for ‘common sense’ approaches. They were confounded by the conclusions that other practitioners came to, particularly where ‘lifestyle choice’ was a factor. Many practitioners appeared confused about the MCA itself (House of Lords, 2014), which very much frustrated other practitioners. There was often lack of consensus around assessment decisions (Clerk et al, 2018).

I was also able to identify a belief held by many participants, that other agencies deliberately manipulated MCA assessments to suit their agency agendas and financial situation (see Figure 27). The accusation of ‘wanting’ to find capacity to permit inaction was usually directed towards to social services, and often seen as ‘political’ because ‘incapacity costs’ (Housing Officer). The MCA was seen as having given a ‘green light’ to do nothing. Thus, effectively it is being argued that the MCA has been pressed into the service of the austerity agenda in relation to self-neglect.



'They' *(insert name of professional group)* **want** 'them' *(insert name of person)* to have capacity

'You find as well people who clearly haven't got capacity, they'll say they have'

'It's seen as that's how they've always lived so they've obviously got capacity to continue to make that choice'.

'They' *(insert name of professional group)* **want** 'them' *(insert name of person) to lack capacity*

'I'd say every single case of self-neglect I've had, they *haven't* got capacity, in regards to some professionals opinions'.

'They cannot accept that person has capacity and has the right to choose how to live'.

Figure 24: Summary of participant's views of mental capacity assessments

In 2014, the House of Lords carried out post-legislative scrutiny of the MCA, due to concerns that the Act was not working as had been intended. It found that the culture of paternalism in health, and risk aversion in social care, had prevented the Act 'from becoming widely known or embedded' (House of Lords, 2014, p6). It is difficult to understand these comments in light of this study, as my research found the Act to be both widely known and misunderstood. It is deeply embedded into practice, so much so, that what appears to be a distorted application has become an entrenched heuristic device (chapter 6, sections 6.4.17 and 6.4.18). Rather than being risk averse, social care staff were very often perceived by other agencies to disregard risk in their urge to 'find' capacity and therefore avoid financial outlay. This is consistent with Lipsky's (1980) view that agencies devote energy 'to concealing lack of service and generating appearances of responsiveness' (p76).

There is some limited evidence in support of these findings. The House of Lords (2014) committee heard evidence from the Association of Brain Injury Case Managers who stated that 'assessment of capacity is used as an economic tool to justify lack of provision' (p36). They also took evidence from the Law Society, whose representative stated that she had dealt with cases where presumption of capacity was used to justify inaction, but also ‘many, many cases’ where ‘clients have been deemed to lack capacity because the outcome is going to be that the state spends less on them’ (p36). However, these anecdotes are not supported by research evidence. Ratcliff & Chapman (2016) consider that there is the potential for the assessor’s influence over the vulnerable person to be abused. They do not consider whether there is potential for assessors to game the outcome depending on the agenda of their employing agency.

8.4.3 Section Conclusion

In discussing the first three objectives of this research, I have explored the research findings in relation to how participants understood their roles and responsibilities in self-neglect cases, whether there was a shared language being employed to help participants talk about self-neglect, and whether participants agreed with one another in self-neglect cases. This discussion has focussed on the findings from the ‘problem-sensing’ (Hart & Bond, 1995) stage of the AR cycle. In the next section I will discuss the final objective in relation the action phase of the cycle.

8.5 Objective 4: What do professionals consider as important in achieving successful multi-agency working?

The fourth objective of this research was to explore with practitioners what contributes to achieving successful multi-agency working. The question which was asked of practitioners was ‘What works and what needs changing? In response to this question, this discussion will consider further the content and outcomes of the workshops, as described in Chapter 7.

8.5.1 Content of the workshops

As described in chapter 6, one of the outcomes of the problem sensing (Hart & Bond, 1995) stage of the research, was my development of a set of seventeen 'Headlines', which described the changes to practice that practitioners felt could be made to improve multi-agency working with people who self-neglected. I fed these Headlines back to the LSAB's in order to gain approval for the research to continue and they then formed the basis of the workshops, as described in chapter 7.

To test dependability and confirmability, i.e., were the Headlines reflecting the salient issues, I mapped the Headlines onto Auschra's (2018) diagram of six types of barriers to integrated care (Figure 28). This demonstrated to me that all of the Headlines 'fitted' in to this typology. However, what can be seen from Figure 28 is that the Headlines were clustered around service delivery, organisational and inter-organisational issues. Interestingly, the items which I mapped onto Auschra's (2018) wider barriers of administration, regulation and funding, were seen by participants as those issues which were not 'doable' by them – they could not solve the problem of shared IT systems or lack of funding. The Headlines were also consistent with issued identified in Baxter et al's (2018) review of the literature on integrated care. The Headlines were also interesting in that, similar to the findings of Dickinson & Glasby (2010) they were very much focussed around organisational improvement rather than outcomes for service users.

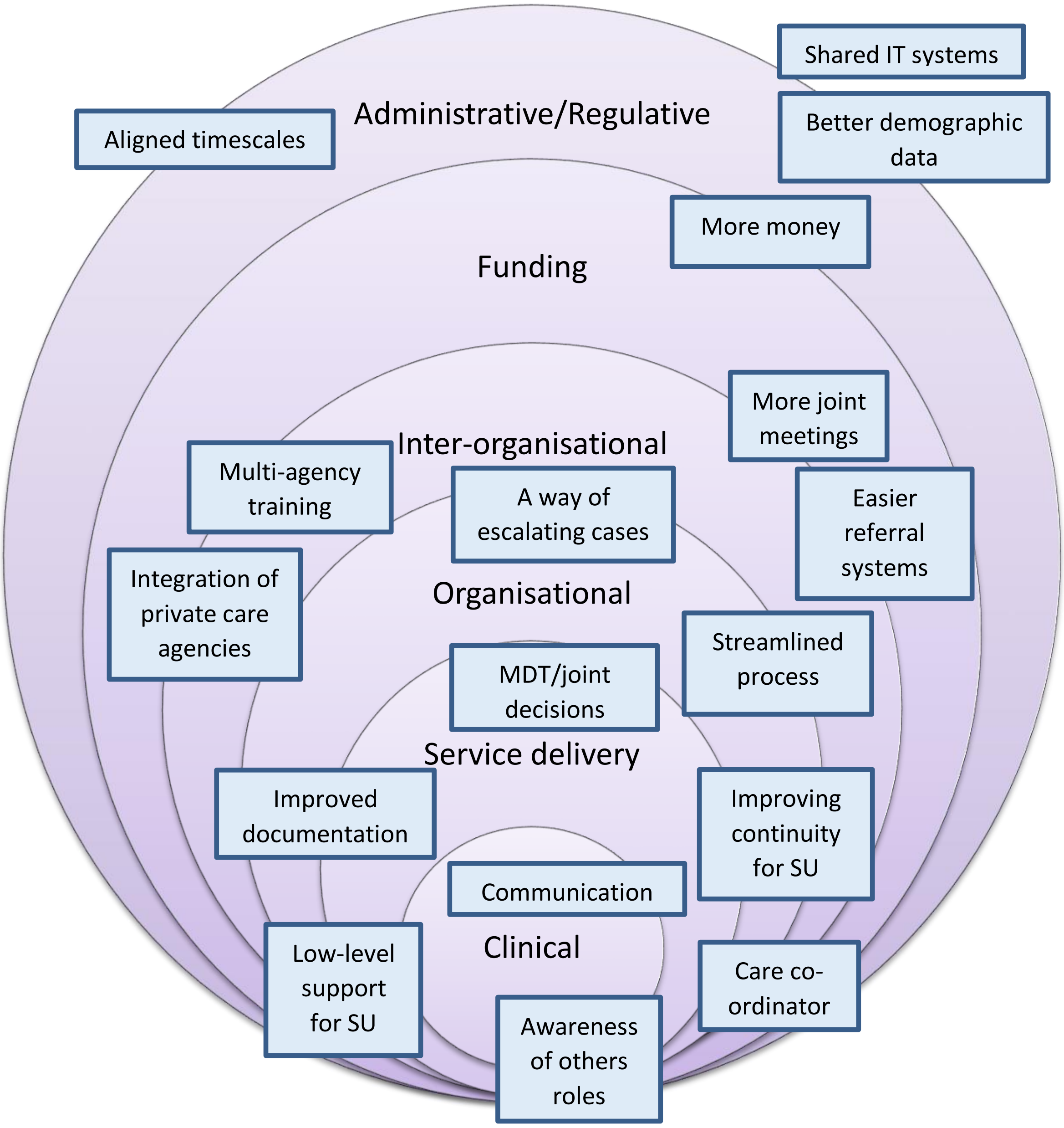


Figure 25: The initial 17 Headline items, mapped on to Auschra's 6 types of barriers to multi-agency working (Adapted from Auschra, 2018)

As described in chapter 7, after discussion in the workshops, I refined the Headlines down to 12 items (see Figure 29), which participants ranked in order of importance and do-ability. I refined the further as the 'top' Headlines from each group were explored further by participants in relation to exactly how the changes they suggested could be made.

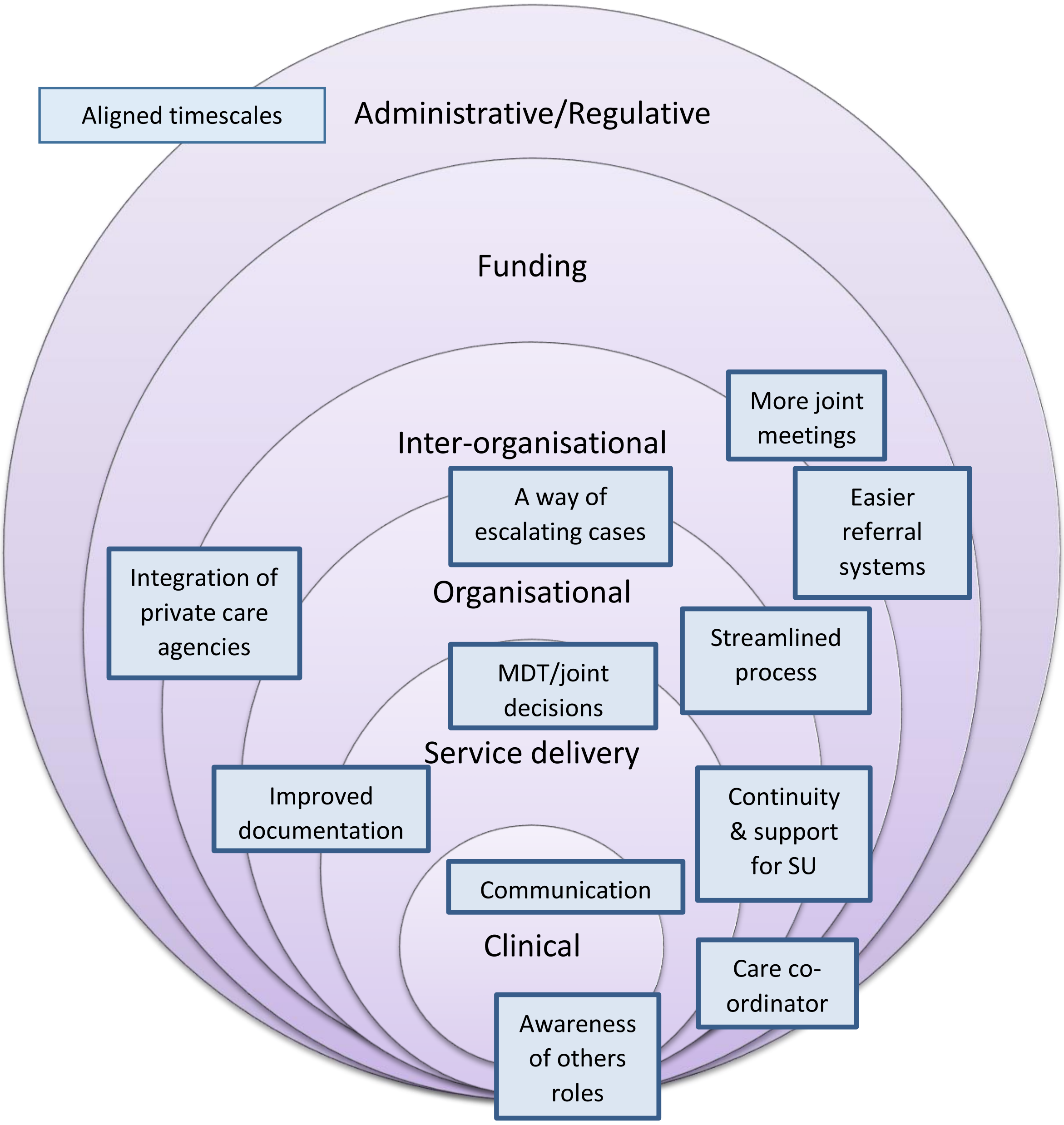


Figure 26: The refined 12 Headline items mapped on to Auschra's 6 types of barriers to multi-agency working (Adapted from Auschra, 2018)

Ten of the Headlines were explored further by the workshop groups (see table 9, priorities selected by different groups, p216). Two were not selected by any of the groups to explore further. In this section, I will discuss the most popular Headline, communication; the Headline directly relating to service users; and the possible reasons why two Headlines were not selected.

8.5.2 What did communication mean to participants?

The ‘Ranking the Headlines’ exercise which participants carried out (described in chapter 7) was completely consistent in that all groups at each workshop placed communication as the top priority for change. This is consistent with recent work carried out by the James Lind Alliance priority setting partnerships (James Lind Alliance, 2019), where practitioners, patients and carers identified improving communication between professionals from different organisations as one of the top ten research priorities for adults with complex care needs. Communication is also identified as a key facilitating factor in many studies of multi-agency working (e.g. Sloper, 2004; Atkinson et al, 2007)

However, I have found, like Suter et al (2009), that communication has many aspects that require clear definition in order to develop meaningful goals. The different dimensions of communication that participants highlighted are shown below.

Table 11: Dimensions of communication and participant action examples

Dimension of communication	Action/solution (examples from participants)
The language that practitioners use	• Discussed previously in this chapter
How individuals communicate face to face, phone, email – the basics	• ‘Pick up the phone – don’t be scared!’ • ‘Be nice! Have respect for other people’s positions’ • ‘Face to face between agencies is better, it reduces hostility’
How their organisations communicate	• ‘Systems which are able to communicate with each other. Vital, especially if more agile working encouraged.’
Where communication can take place	• In meetings – ‘Regular MDT meetings inviting all MDT and people from voluntary agencies as well’ • Joint training and events

Who to communicate with	Basic information about other services, contact names , one point of contact, care-co-ordinator Named contact, key contacts The fount of all knowledge – 'Helps to co-ordinate what everybody is responsible for.'
What can be communicated – what do we need to know?	Referral pathway Information sharing agreements Shared referral form
When communication is happening – timely communication	Clear response to referrals Need to follow up referrals 'Keeping others informed, ensuring you communicate outcomes, no matter what the outcome is.'

Breaking down communication in this way clearly shows how it is linked inextricably to other issues raised by participants. Baginsky (2013) found similarly that though 'good communication' was the most frequently used term in her study, without being defined further, participants connected it to both practical issues and shared understandings and meanings. This circular linkage was highlighted on several occasions. The dimension of 'who to communicate with' involved discussions of having a care-coordinator. This was also identified as a separate Headline and one that could have advantages for the service user as well as the professional (Dickinson & Glasby, 2010). Goodwin et al (2014) showed that, for service users, having a care co-ordinator was more effective than telephone support or remote monitoring.

The dimension of 'where communication can take place' included the suggestion of more MDT meetings. However, 'more meetings' was also identified as a separate headline by my participants, and as part of this, suggestions were made for improving communication in meetings, such as having a timed agenda. The notion of more meetings is rather counterintuitive, as it might have been assumed that participants would want fewer meetings, to allow them time to get on with the job. However, Horwarth (2007) describes that professionals who were limited to written or telephonic communication, and who had less opportunity to meet, were more likely to make inappropriate decisions about referrals, so meetings may be very important. Participants in my study were very frustrated by the availability of other professionals, and by lack of feedback from referrals (Horwath, 2007), and they clearly wanted greater opportunities for meeting together and for discussion,

> Saves time in the end. People tend to say that meetings are a nuisance, but actually they are one of the best things you can do in my own opinion (Social Worker).

Cameron et al (2014) reinforce this in their summary of studies, which have shown how effective communication can lead to better outcomes for service users, more efficient prioritisation of cases and more timely assessments. Kim et al (2017) found that where communication breakdown occurred, this could result in withholding information from others, and this was also evident here.

As can be seen from Table 11, some of the solutions to communication difficulties proposed by participants were relatively straightforward and cost neutral, indicating that improving aspects of communication is potentially possible. However, whilst the catch-all phrase ‘communication’ continues to be used indiscriminately (Baginsky, 2013), rather than broken down into its various dimensions, there is a risk that tackling the minutiae of problematic communication issues will be seen as too difficult. One common solution proposed for communication problems is that of co-location of staff (Mackie & Darvill, 2016). This may work reasonably well where two or three groups of professionals are being co-located, though the evidence is equivocal (Auschra, 2018), and some professionals in my study reported that co-location did not eliminate data sharing issues (McCreadie et al, 2008),

> Social Services have a system which we've had training in, but somebody hasn't rubber stamped the fact that we can actually use it, so we rely on S or whichever colleague is in to look at the system (Nurse in an integrated team).

However, co-location is often not feasible in truly multi-agency situations, such as described here, and thus communication barriers must be tackled in a different way.

8.5.3 Other areas identified which link to communication

No other Headline was identified uniformly across all four workshops. However, the headline 'Making it easier to contact and refer to other agencies' was explored by three workshop groups. In the circular process described above, this relates fundamentally to timely communication. In the group interviews I had noted several frustrations being raised about this aspect of MAW, relating to both making referrals and receiving referrals. The simple mechanics of making multi-agency working a referral were mentioned ('you phone the number, not there, they phone you back, you're not there, it's a slow process' (Community Nurse)), and the frustration of not having a named contact or knowing who to contact, of being 'sent round the houses' (CMHN), being 'blocked by the call handler' (Housing Officer). However, other frustrations related to the lack of acknowledgement that where another professional was making a referral, their professional knowledge was not respected, or even allowed for,

> I've had ...tried to make an internal referral, pick up the phone, but you need to fill this form in and that form in, we need all this detail, and I'm like, I'm not filling that in, an eight page form, I'm speaking to you on the phone now. 'Give me this information'. And I walk away from it then (Environmental Health Officer).

Thus, frustration and resentment is present even at this very early stage of the multi-agency working process. These feelings increase when referrals are received which contain incomplete or misleading information, and appear to be trying to 'pass the buck'. The metaphor of battle was also used to describe making referrals, where 'it's case of firing them through' (CMHN), presumably until they hit their intended target. However, issues specifically appertaining to referrals are rarely mentioned in the literature. Participants had excellent ideas about how referral processes could be improved, as the World Café task demonstrated, such as using a generic referral form for all agencies, or developing a service directory to which all agencies could contribute. This latter suggestion highlights the discussion earlier in this chapter about lack of understanding of one another's roles, which it was felt a service directory could facilitate.

8.5.4 Improving outcomes for people who self-neglect – continuity and support for the service user

The Headlines which I developed were also interesting in that, similar to the findings of Dickinson & Glasby (2010) they were very much focussed around inter-organisational improvement rather than outcomes for service users. However, two of the four workshops did choose to look at how direct work with people who self-neglected could be improved. Originally I had used two headlines relating to service users, one which related to how best to engage service users, the other which related to the provision of low-level services, to prevent a crisis occurring. The latter issue was highlighted similarly in Braye et al's (2013) workforce development study.

For many participants, a discussion of low-level services was meaningless, because, as a result of cuts, there were no services left in the area to provide low-level support, 'little lower level preventions would have prevented that. That's all gone now' (Social Worker). However, at the first workshop, discussion of this highlighted to me that actually making contact and getting service users to engage was seen as very important. Thus, I amalgamated two headlines, and in the event, we focused very much on how to engage with service users. However, there were interesting differences in the responses of the two groups.

Table 12: Engaging with service users who self-neglect: LA1

LA1: Engaging with the service user/preventative services	
1. Keep trying 2. Ask them 3. Building a good relationship 4. Refer to self-neglect panel 5. Use social media 6. Send a letter first 7. Visit at different times of day 8. Vary venues to meet – middle ground? Neutral space? 9. Right person with right skills 10. Persistence 11. Engaging others friends/families/neighbours 12. ‘card in the window’	13. Previous professional engagement, ‘good rapport’ 14. Friendly and personal notes and messages rather than intimidating official letters 15. Text message 16. Go with the preference of the client, e.g. phone call? Letter? Time of day? 17. Making every contact count, e.g. housing officer, plumber. 18. Successful contacts? 19. Not discharged from service from non-engagement (DNA)

Table 12 shows the LA1 group suggestions for how to engage with service users who self-neglect. The suggestions all tend to be extremely practical and based around the liminal space between the outside world and the interior of the service user’s house. They were very concerned with the way in which an approach could be made. Participants had expressed concerns in the group interviews that people who self-neglected were less likely to respond to usual methods of communication (they would not open appointment letters for example), and were more likely to be discharged from services for non-engagement. However, as Table 13 shows, responses by the LA2 group were of a very different nature, much less focussed on gaining entry and much more focussed on the value of early intervention, and the therapeutic relationship. These responses have resonances with the work of Dickinson & Glasby (2010), in terms of being more aspirational than practical. This group also considered the role of multi-agency working, and particularly the third sector in supporting people who self-neglected. Again though, there were many good suggestions for how to intervene, though the responses of the LA2 group may be more difficult to achieve.

Table 13: Engaging with service users who self-neglect: LA2

LA2: Engaging with the service user/low level services	
1. Helps to reduce the risk of escalation/deterioration 2. Keeping contact with service user 3. Which professional will develop this relationship? 4. Developing trust with patient/client 5. Maintaining contact could stop the situation escalating 6. Creating empowerment 7. Third sector feeding information to professionals about at risk people 8. Building therapeutic relationships 9. Regular visits 10. Having the time to visit on a weekly basis to build up trust 11. Caseload management and preventative work considered priority-wise 12. Working together to engage with service user and supporting services 13. Not placing too high expectations on individuals and working at their pace. 14. Early intervention at a low level, maybe community access to voluntary sector, build up self-esteem and confidence in the hope this could reduce crisis situations 15. Closer communication and links with support agencies who can provide low level support 16. Door to door service to identify those potentially at risk to help provide early intervention	17. Being patient, persevering in contact 18. Understanding the psychology of self-neglect. Be prepared to try different engagement techniques 19. Due to high level of referrals to services this can be difficult, but maybe there should be a ‘list’ in each team of who is at risk of self-neglect so they can be prioritised even though other service users may present more imminent clinical risks. 20. This comes quite high – it’s a preventative measure to minimise low level becoming high. 21. Being able to keep patients on your caseload to address this 22. Consistent approach when engaging 23. Doing a support plan can be a valuable tool. Looking at the following: What’s working for you? What’s not working for you? What needs to stay the same? What needs to change? What is important to you? What’s important for you? Once some of the underlying causes are identified, this can be very valuable. 24. Initial contact, phone call, email, text, non-verbal/pictures (preferred method of communication) 25. As my patient would not let me in the house, I phoned them weekly to maintain contact.

I found that it is perhaps a weakness of the World Café (Brown & Isaacs, 2005) technique (or my adaptation of it) that the responses of the first few people to write down their thoughts may set the tone for subsequent participants who read earlier responses, and adjust their contributions accordingly.

8.5.5 The unexplored Headlines

There were two Headlines that no group chose to consider further in my workshops. These were 'Aligned timescales' and 'Integration of private care agencies'. I had noted that aligning timescales had been much discussed in the group interviews, as a source of frustration, though this was much less about formally measured timescales than perceptions of difference in how an urgent situation was defined, or the frustration of a referral being caused 'by another agency's solution to the problem' (Braye et al, 2013, p41). Thus community nurses, who had to respond to referrals within a few hours, were perplexed by social services and mental health services, who were *'*a bit slower, and a bit, perhaps, chilled with it'. Similarly, paramedics, who needed responses in a hurry were frustrated because*,*

> Other bits of agencies are quite good at, well we're not coming out because it's after six o'clock or it's a Tuesday and the winds blowing in the wrong direction and whoever's not on, so other agencies just aren't taking part today for some reason (Paramedic).

Conversely, social workers reported situations described as urgent by others, which in their view were not. Both the police and paramedics were frustrated by having to pick up complex cases out of hours or at weekends, where there was no back up from other services, and one paramedic suggested 24 hour services were the only solution.

Reflective stop off
I wonder if perhaps participants shied away from discussing timescales because it was an area that had real potential to cause arguments in the workshops. Certainly, looking at the interview transcripts, it was an area which caused strong feelings, and where 'names were named'. Perhaps participants felt it was too difficult to address in mixed professional groups in the workshops and that it was better to keep the peace by sticking to subjects that were less controversial. This is an area that deserves much wider exploration, perhaps in different circumstances.

8.5.6 Why didn't they care about domiciliary care?

Since the community care reforms of the early 1990s, day to day care of many vulnerable service users living at home has been largely provided by staff from second and third sector organisations rather than directly by the NHS or social services. Most of these companies depend on contracts from the first sector to operate, with 90% of care agencies being private (Ghibelli et al, 2017), and in turn, social services and the NHS rely on these agencies, particularly to support older people (Fernandez & Forder, 2015). There is scant evidence about how this ‘creeping change’ (Thomas, 2015, p196) to multi-agency working has been received by practitioners. In their studies, McCreadie et al (2008) and Thomas (2015) note a lack of engagement with the second (for profit) sector and third sector by first sector organisations. Thomas (2015) attributes this to the public sector being seen as occupying the ‘moral high-ground’ (p200) having traditionally been viewed as the best organisation to provide services. I found that the poor integration of home care agencies was discussed in the interviews, for example, by one group of nurses, who expressed frustration that ‘you never know which agency is going to be looking after a patient’, and suggested that nursing teams should be ‘paired’ with an identified agency. Domiciliary care staff who were interviewed, demonstrated an awareness of their second class status, and described how they battled against the ‘hidden power’ (Hathaway, 2016, p120) in being kept out of the information loop, ‘you're just a care provider, you shouldn't have that sort of business or information’.

This was therefore, clearly an important issue. Participants choosing not to explore this Headline further in the workshops could be seen as a manifestation of this ‘hidden power’ (ibid), or of other practitioners being unwilling to cede the ‘moral high-ground’ (Thomas, 2015, p200). Yet in the case of service users who self-neglect, this could be considered a wasted opportunity to strengthen a very important working relationship. During the interviews, I had experienced domiciliary care staff describing being involved in the support of many service users who self-neglected, relationships which had developed over long periods and where service users clearly had trust in the worker. This could provide invaluable knowledge and support for the other professionals involved, but appeared to be sorely overlooked. As one nurse put it, ‘we do have a lot more shared cared working with agencies, that's at its infancy, so it probably needs more development'.

8.5.7 Why was action planning difficult?

Overall, although the literature on multi-agency working is clear about the barriers that may be presented discussion of how the barriers might be overcome is much less common, with Mackie & Darvill's (2016) work being a notable exception. However, in all of the areas that were discussed in the workshops, practitioners were clear about how barriers could be overcome, and had many suggestions about what changes could be made to improve multi-agency working with people who self-neglect. However, what clearly presented difficulties in each workshop, was how to set about putting those changes into practice. As described in chapter 7, at the action planning stage, practitioners appeared reluctant to commit themselves or their agencies to taking on tasks, even if it was seen in discussions as a good idea. For example, although the role of care co-ordinator for people who self-neglected was enthusiastically received, participants expressed the view that they were afraid of being 'lumbered' with what the role might entail.

On reflection, I wondered if this was an example of what Mackewn (2008, p623) described as the 'whole system impinging on the focal group we are facilitating'. For the period of the workshop, we had been able to work creatively and productively together, in a multi-agency environment with many differences of status between individuals and professional groups. But once the 'whole system', the reality of the outside world was re-admitted, it was harder for participants to commit themselves to potentially difficult changes, which might bring them into conflict with other agencies, and ultimately make more work for themselves. The 'choreography of energy' (ibid, p624) had shifted. In chapter 4, I described how Cornwall & Jewkes (1995) argue that researchers move from different modes of participation during the research process. I felt that when the workshops were at their best, we were at a truly collegiate level, working together in a process of mutual learning, and where participants were in equal control. However, when considering the ways forward from the workshops, participation became more consultative, with participants being clear that change was now out of their control. Facing a similar paradox, where enthusiasm was ignited and then blocked, Wadsworth (2001) reports that, 'we had eventually to conclude that the transformative energy was not able to come from staff alone in sufficient degree to be effective' (p326). In Noga et al's (2016) action learning study, this 'can't do' (p11) attitude was not challenged by other group members, but instead met with sympathy as a reasonable reaction.

Reflective stop-off
It felt very much to me that the emphasis on trying to improve outcomes for service users got lost in the rush not to accept responsibility for making any organisational changes. The question being asked was 'will this make more work for us?' rather than 'might this improve things for service users who self-neglect'. On reflection, I think it may have helped if I had encouraged the participants to think through more clearly what improved outcomes for service users might look like, for example, avoidance of admission into residential care, or an improvement in physical health. However, that would assume that all of the participants agreed about such outcomes, which when I had explored this further in relation to writing my 'researcher identity memo' (Maxwell, 2013), I had concluded that they did not.

Noga et al (2015) found that members of their action learning group began to become dependent on the facilitator, and resisted taking the lead themselves. They speculate that this reluctance to assume responsibility charge was because the members had not set the agenda themselves. This was not true in my study, where participants at the workshops were working with an agenda that they themselves had set, yet they were still reluctant to take charge and further that agenda. It appeared that participants, as they had in Noga et al's (2015) study found the question 'how can things be done differently' was difficult and daunting.

8.5.8 Individual changes to practice

As discussed in Chapter 7, one of the tasks that practitioners at the workshops undertook was the completion of ‘change promises’, which I followed up six weeks later by email, to see if participants had been successful in their objectives. These produced very positive responses, and on reflection, made me consider whether, in the current neo-liberal climate, individual change to practice as a result of AR is a more realistic aspiration than wider change, to help practitioners ‘speak back to the culture of fear’ (Stanford, 2010, p1068). It may be that it is of more relevance to try to help people feel more confident and empowered in their practice, and promote professional autonomy and the determination to develop and sustain caring relationships, and more able to practise in a way that was consistent with their values (Smith et al, 2017). The themes that emerged from the change promises indicated that this was the case. These were,

- Increasing own knowledge and learning.
- Making personal changes.
- Helping others increase their knowledge
- Better joint working.
- Changes to mental capacity assessments.

Increasing knowledge and learning was a very empowering aspiration, and it was interesting that several respondents also wanted to help others to do this. In relation to the growth and change implied by ‘making personal changes, several people mentioned wanting to make changes in their ‘ways of thinking’ (Social Worker), to ‘not be afraid to speak out’ (Homelessness worker). This was not written as being in relation to self-neglect, simply as an aspiration of its own. Another person had begun to see the conflict within her job role, and now wanted to discuss this with their manager. One Social Worker wrote that they were going to endeavour to ‘make sure that I am exercising professional curiosity on self-neglect cases’, which was encouraging in relation to developing caring relationships and Burton & Revell’s (2017) point above. Others said they were going to consider their own values, think about how they listened to service users, and try to understand the implications. These were important issues.

Although the workshop groups had found it very difficult to formulate action plans, there were many 'change promises' which correlated with 'how to' suggestions made during the World Café exercise. For example, in relation to communication, promises included changing how they made referrals, being better at information sharing, and, in one case, developing a directory of resources.

It was clear from the responses at 6-week follow-up, that people had taken the promises seriously, and had thought about how they were going to implement them, and in several cases had done so. Others were going to take longer, or were not so tangible. However, these changes in individual behaviour are commensurate with Stuart's (2012) findings from an AR project, behaviours that ultimately enhanced collaboration.

8.6 The overall context of the research and the wider picture

8.6.1 Are there pre-requisites for successful change in an action research project?

In exploring the literature in this area, I found little that addressed the issue of whether there were pre-requisites for change in an AR project, which might aid an understanding of why participants had been reluctant to shoulder the responsibility for changing aspects of how they worked together. Preston-Shoot (2018), in his discussion of recommendations for changes made by SAR's, concludes that barriers such as turnover of staff, lack of resources and heavy workloads will frustrate organisational changes in safeguarding processes. Phillipowsky (2018) similarly argues that meaningful change cannot happen unless issues concerning accountability, responsibilities and risk management have been addressed. However, it may be debatable whether these conditions are ever achievable, particularly in the climate of austerity and uncertainty (Suter et al, 2013) which all of the organisations in this study were experiencing. Pearson & Watson's (2018) analysis of the early experience of implementing integration across

Scotland found that a central theme in implementing change (or not) was participants being 'too busy doing the day job' (p401).

Sparrow & Robinson (1994) write that the success of an AR project in bringing about change relies on many other factors than the researcher's interest. There has to be, they argue, sufficient motivation to change amongst the staff involved in an AR project, a strong commitment to change, and not too many other besetting problems. Waterson (2000) believes that consideration must be given to whether the issue being examined ranks highly enough amongst other concerns for practitioners. I would argue that the issue of self-neglect increased in its concern ranking as the research progressed, and practitioners wrestled with self-neglect becoming part of safeguarding legislation. The high rates of interest expressed for workshop attendance would indicate that it did. Yet despite self-neglect ranking highly as a concern, the other besetting problems that practitioners were experiencing jeopardised the possibility of change because of the study.

8.6.2 Action research seeks change - within wider change?

Reflecting on the workshops, I began to wonder whether it was feasible to expect participants to be able to engage in change to working practices identified by research, as the model of professionalising action research envisages (Hart & Bond, 1995). It was evident they were already engaged in a complex situation of wider change, on both a local and wider political level within their organisations. AR tends to assume a stable state before the change happens, but this may not be the case, and it raises questions about participants' capacity and willingness for change. In addition to his seminal work on action research, Lewin (1951) developed a model of planned change, which is still the foundation of much of the theory around organisational change, and which sits alongside his theory of action research. It conceptualises the process of change as that of *unfreeze - change – refreeze* (Lewin, 1951). The model has been much criticised (Burnes &

Bargal, 2017), with Kanter et al (1992, p10) referring to Lewin's theory as 'the organisation as an ice cube' and criticising its inflexibility. However, it is also much defended (Cummings et al, 2016), and Suter et al (2013) argue that is has potential to inform inter-professional working practice, but has not been much applied. Its relevance to this study is that it assumes there is a state, prior to intervention, where organisation and employees are frozen, in that they have not been able to change as fast as the operating environment demands, and they are experiencing inertia (Burnes, 2017). Lewin (1951) argued this presented the need for unfreezing, a process of letting go of attachments to current beliefs which become unsustainable or inappropriate (ibid). A belief that by public sector employees such as social workers, that they occupy the 'moral high-ground' (Thomas, 2015, p200) might be an example of this. However, as an outsider carrying out research with the many organisations in this study, on reflection I believe the ability of participants to engage in the change which the research indicated was possible, was compromised by levels of change that people were already experiencing in their work. To borrow Kantor et al's (1992) metaphor, the ice cube had already melted when my research began. Two participants described these personal recalibrations,

> But that's the way it happens in any period of change, but the change in the health and social care sector is massive at the moment, isn't it, and it's not going to stop, so it's something you have to live with (Occupational Therapist).
>
> We have to change as well with that, don't we? We have to work with that because it has changed, it can't be like it was. People say "the good old days" it's not like that, so we have to accommodate and try and work what the situation is now (Social Worker).

Potentially then, AR will be hindered if there are too many other problems in the landscape (Sparrow & Robinson, 1994), yet it is hard to know how it can be determined when the line gets crossed. A strength of action research is that it addresses the question of what is the local reality in the area in which the study is taking place (Herr & Anderson, 2015), but at the same time, the national context in which research is taking place cannot be ignored. On reflection, I see that the context in which the research took place could have been argued to be mitigating against successful change, because the motivation for change, which this particular project offered, had been compromised by significant local change, and by the constant, wider change that participants were experiencing, as Ling et al (2012) identify. Badger (2000) echoes this, in stating that the experience for staff within the NHS is one of constant change, where stasis is never achieved.

Burnes (2017) writes that unless people concerned with change feel psychologically safe from humiliation or loss, they will resist change. In Chapter 6, section 6.4.13, I discussed the fear which participants expressed about being humiliated, 'having the finger pointed at you' (Housing Officer), and the loss that would ensue from errors, such as loss of professional registration, job, and home. Auschra (2018) argues that people may resist change to inter-organisational collaboration 'if they do not see the usefulness of the collaboration or fear the loss of their own professional existence' (p8), or if they feel change is being forced upon them. The latter points were borne out by a participant working in Homelessness services, who commented that, 'NHS England would do well to come down and see what we work with, they take away our security'. Thus, resistance to change may potentially hinder AR (Montgomery et al, 2015).

I carried out my study in two different local authority areas, because I felt this was prudent in case one chose to drop out during the study. In the event, I worked extensively in both areas, and neither area dropped out. However, I could not have predicted the changes that would take place both locally and nationally during the three years in which I was conducting the study. These changes raised key questions that had not been anticipated at the start of the research. These were about the ways in which AR may be jeopardised by factors outside the researcher's control, as McLaughlin et al's (2007) AR study also found, and how the potential for bringing about change through AR may be lessened or nullified, according to the context of the research.

8.6.3 Action Research in a local context

When I reflected on the changes which participants had experienced in their working lives during the period of the research, it was clear there were some important local factors,

- All of the social work staff in one authority transferred employer to a local health trust during the research. This change of employer caused great uncertainty amongst participants.
- The LSAB in one authority amalgamated with three other authorities, who were not in the study. This meant that key people who were familiar with the study no longer participated in the LSAB, and continuity and momentum were lost.
- One housing provider that had taken part in the interview phase subsequently lost their contract with the local authority and had to withdraw from the research.

Unforeseen 'human' events can also have an impact. During the interview phase of this research, two deaths occurred in a house fire of a couple who were severely self-neglecting. Although this was in a neighbouring authority and not in an authority directly involved in the study, the deaths were widely reported. On reflection over a period of several months, I could see that this had an impact on practitioners and on the LSAB (which now included the authority where the deaths had occurred, because of the amalgamation of the Boards), in terms of increasing the risk adversity of practitioners, and potentially permitting greater statutory intervention. One result, for example, was that the coroner for the region wrote to the Home Secretary to ask for legislation to be amended to allow fire services to enter people's homes without the homeowner's permission (Rebello, 2017), despite this being a direct conflict with human rights' legislation. Sparrow & Robinson (1994) consider that where there are anxieties connected with the area of work, resistance to change will be increased. Working with people who self-neglect has been seen to be an area of work which causes practitioners much anxiety, and it could be postulated that an event such as this increases resistance to change, by confirming people's existing belief systems (Burnes, 2017) and making any change to how things are done seem more risky. Conversely, it could be argued that such a catastrophic event was a clear indication that the system for protection of vulnerable self-neglecting people was not working, and changes needed to be made.

8.6.4 Action research in the wider context

The wider political climate must be considered a factor which will potentially undermine both individual practice (Burton & Revell, 2017), joint working (Cameron & Lart, 2003) and AR (Anderson, 2017). The financial strictures imposed by the so-called ‘austerity’ (Holborow, 2015) agenda since 2010 are clearly key in forming the background to this study. For example,

- By the end of the financial year, 2018/19 Local authorities will have had to save £7 billion from adult social care budgets since 2010 (ADASS, 2019).
- There have been 220,000 redundancies of local authority employees between 2010-2018 (Butler, 2018)
- Direct government funding for the police fell by 11-25% during the same period (Home Office, 2018), with workforce cuts of 18%.
- Public sector pay was frozen for two years in 2010, except for those earning less than £21,000 a year, and since 2013, rises have been capped at 1% below the rate of inflation until 2020 (BBC News, 2017)
- Although NHS funding was ring-fenced, the NHS was required to make 20bn efficiency savings by 2014/15 (Appleby, 2014)
- In 2017, the Royal Society of Medicine reported that government austerity decisions in health and social care were likely to have resulted in 30,000 deaths in England and Wales in 2015 (Watkins et al, 2017)

Baginsky (Baginsky et al, 2009; Baginsky, 2013) carried out two studies of joint working, and found that the number of respondents who identified the impact of budget cuts on their agency as a barrier to joint working went from 29% in her 2009 study, to 68% in the 2013 study. All of the agencies who took part in this study have been subject to unprecedented budget cuts. The fears expressed by practitioners in this study about losing their jobs and their livelihoods are, therefore, very real.

8.7 Trustworthiness and authenticity of the study

In chapter 4 I explored the concept of validity in relation to AR, and concluded that consideration of trustworthiness and authenticity were perhaps more meaningful for AR (see Appendix 3 and 4). I have discussed these concepts in several chapters, and Table 14 summarises the key ways in which my study met the criteria for trustworthiness.

Table 14: Components of trustworthiness and examples of how they are demonstrated in this research (adapted from: Lincoln & Guba, 1985; Schwandt, Lincoln & Guba, 2003; Shenton, 2004; White, 2014)

Component	Demonstrated by?	Example from this research
Credibility	Prolonged engagement	The fieldwork for this research took place over three years. Some participants were involved in the group interviews, the initial workshops and the subsequent workshops
	The development of an early familiarity with the culture of participating organisations	Already had direct familiarity with the culture of one organisation, and quickly developed familiarity with other organisational cultures
	Sampling strategy	Use of non-probability purposive sampling
	Triangulation	Site triangulation Triangulation of methods (group, individual and paired interviews; workshops) Triangulation of theory
	Tactics to help ensure honesty in informants	Assurance of confidentiality and anonymity, no identifying details recorded on transcripts.
	Iterative questioning	Use of iterative questioning in interviews and workshops
	Peer scrutiny of the research project	Regular presentations to the LSAB Participatory data analysis Involvement of new participants in workshop phase
	The researchers reflective commentary	Journal extracts and reflective 'stop-off's' provided throughout the thesis
	Examination of previous research findings	Demonstrated in literature review and discussion chapters
Transferability	Thick description of the phenomenon under study	Used different types of interview configurations, and carried out a substantial number of interviews. Data from a total of 4 workshops also used
	Providing the boundaries of the study	All of this information is provided in chapter 5, except where confidentiality concerns do not allow.
Confirmability	Triangulation	See above
	The extent to which the researcher admits their own predispositions	See discussion of positionality, chapter 5
	Reflective commentary	See reflective stop-offs and journal entries throughout the thesis

Dependability	Recognition of shortcomings in study’s methods and their potential effects	Provided in chapter 5
	In-depth methodological description	Provided in chapter 5
	Audit trail – data oriented approach, and a theoretical audit trail	Provided in chapters 4 and 5
	In-depth description of research design, data gathering, reflective appraisal, overlapping methods	All described above NB. Lincoln & Guba (1985) argue there are close ties between dependability and credibility.

This study was located in a small geographical area and its focus was on local relevance (Dick, 2015). Because AR is so influenced by local context, it may be argued that its transferability, or the possibility of applying the outcomes of the study to other contexts (Stringer, 2014) is limited. However, Greenwood (2015) argues that although AR often takes place in what seem like highly idiosyncratic circumstances, these are very valuable learning experiences to be applied to future cases or problems in other areas. To enable transferability, the reader of the research needs to be able to make the ‘transfer’ so information about the research site must be included. However, there is a conflict here with confidentiality and anonymity, meaning that there is much about the research site and participants that cannot be disclosed. I would suggest this is particularly acute for AR, where participants may be more deeply involved than in more conventional research.

Participants were extremely honest with me, particularly in the interviews, and I felt a great responsibility to respect and honour their trust in me, by being circumspect and careful in how I used and attributed their words. This, it could be argued, has an impact upon transferability, and as the researcher, I accept that. However, I would also argue that it is the responsibility of the researcher to make their research as transferrable *as possible* by trying to disseminate it widely in the public domain (Gray, 2014), and listening to and learning from the response that is received. I have tried to do this by attending conferences, both academic and professional, throughout the research, and feedback I have received at such events has caused me to reflect and consider, thus strengthening the research.

Demonstrating authenticity has been more challenging. I have found that it is much more linked with my own reflexivity, in terms of trying to develop my awareness of what was happening and what it meant to people. This is difficult to capture, and in the following table I have used direct quotes from participants to try to illustrate the different components.

Table 15: Components of authenticity and examples of how they are demonstrated in this research (Adapted from: Lincoln & Guba, 2003; Shenton, 2004; White, 2014; Bryman, 2016)

Component	Demonstrated by?	Example from this research
Fairness	Ascertaining and presentation of different value and belief systems represented by conflict over issues Negotiation of recommendations and subsequent actions with stakeholding groups.	Discussion of conflict identified in interviews and explored by iterative questioning, is described in chapter 6, and discussed in chapter 8. Presentations to LSAB's throughout the research
Ontological authenticity	Does the research help members to arrive at a better understanding of their social milieu? (Bryman, 2016, p386)	Demonstrated by responses to interviews, feedback from workshops and individual feedback on steps taken leading to change. 'That got my brain working. I shall start thinking now, I can see what they're saying, what are they actually asking me?' (Community Nurse, following interview)
Educative authenticity	Does the research help members to appreciate better the perspectives of other members of their social setting? (ibid)	Demonstrated by responses to workshops 'Gaining the perspectives of other professionals, specifically understanding their frustrations and boundaries to integrating/joint working.' (Participant feedback from workshop) 'Great to see how many different job roles think and act differently according to situation and individual perception' (Participant feedback from workshop)
Catalytic authenticity	Has the research acted as an impetus to engage in action to change their circumstances? (ibid)	Demonstrated by responses to individual change pledges 'I will Interact with professionals in other agencies more – i.e. multi-disciplinary working' (Housing officer)
Tactical authenticity	Has the research empowered members to take steps necessary for engaging in action? (ibid)	Demonstrated by responses to individual change pledges 'We're gonna break some new ground here aren't we?' (Response from LSAB member after presentation to Board)

From the perspective of authenticity, this research demonstrates a high level of both ontological and educative authenticity, as people learned about themselves and about each other. However, as I described above, achieving tactical authenticity was much more difficult, as participants themselves found it difficult to take the necessary steps for engaging in group action.

8.8 Conclusion

In this chapter I have synthesised my findings from both the ‘problem sensing’ stage of the research (the group interviews) and the action research cycles (the participatory workshops) with the literature review. I have linked findings and literature under each of the four research objectives.

In relation to objective one, I have discussed my finding that not only did participants not understand the roles and responsibilities of others, they often did not fully comprehend their *own* roles in multi-agency working with people who self-neglected. This caused particular problems around the operationalisation of legislation, and resulted in indignation, frustration and blame. In my discussion of objective two, concerning a shared language, I have identified seven dimensions of problematic communication, and found that in practice, participants experienced a paucity of language and a reluctance to discuss particular aspects of a self-neglect situation. I have concluded that to overcome these problems, practitioners resort to unhelpful euphemisms, particularly the trope of ‘lifestyle choice’, but that this in itself caused conflict and frustration with other professionals.

In relation to objective three, I have extended the literature on conflict in multi-agency working, through discussion of my findings on the genesis of conflict and the strategies which practitioners had developed to manage this in their multi-agency practice. I have highlighted how fear drives defensive practice, particularly in relation to enacting legislation.

Objective four of this study examined what professionals considered as important in successful multi-agency working. This was mainly related to the four participatory workshops which I have facilitated as part of this research. The overwhelming area of concern for participants was communication, and I have discussed the participants views of the actions they could take to change and improve some of the most problematic areas. I have also discussed engagement with service users, which was identified as a priority issue. However, I have moved on to consider why participants found it difficult to put their ideas into action in the group setting, compared with the successful changes made by individual participants post-workshop as a result of the ‘change promises’ that participants made.

In the final part of the chapter I have considered the context in which this AR was carried out. I have discussed whether there were pre-requisites for successful change in an AR project, and whether change as part of an AR project might be jeopardised by the demands of wider change, demands to which most of my participants were subject. I have discussed the local and national context in which this AR took place, and have concluded by showing how this study demonstrated trustworthiness and authenticity.

Chapter 9: Conclusion and contribution

9.1 Introduction

In this chapter I will set out my overall conclusions related to my original four research objectives and highlight the contribution to knowledge made by this research. I shall consider the strengths and limitations of this research. I will provide recommendations for both practice and for further research. I will reflect on my own personal journey and development as an action researcher and conclude by briefly discussing further developments which have taken place subsequent to what is described in this thesis.

In Chapter 1, I described the ‘wicked mess’ of self-neglect and multi-agency working. What brought me to this research topic was my belief, gained through talking to practitioners, reading and reflecting, that it was very important to try to look at ways of working with the ‘wicked mess’. In this conclusion, I will consider whether and how this research has begun to do that, in a specific local context. As Head & Alford (2015) argue, although solutions to such wicked problems are rare, it is possible to go some way to framing possible courses of action against them. Conklin (2006) says, rather than ‘solving’ such problems, it may be feasible to ‘help stakeholders negotiate shared understanding and shared meaning about the problem and its possible solutions (p5). That is what I have tried to do here, using an AR approach.

9.2 Contribution to knowledge

This thesis makes a significant original contribution to knowledge from two particular perspectives.

The first is my contribution to the subject matter. There is a lacuna in the literature on how cooperative working in self-neglect is experienced by those who are actually engaged in it. This study fills that gap by contributing to the discourse on the subject of multi-agency working with people who self-neglect. It is the first study to include the views and input of the full range of agencies who might typically work with people who self-neglect. It offers a unique perspective on the beliefs of practitioners about each other. Working with people who self-neglect is located within safeguarding adults work, which itself is located within a multi-agency working context (see conceptual map on p86). I have contributed to, and extended the discourse on multi-agency working in four main areas; inter-agency conflict, inter-agency communication, professional role understanding, and achieving change in multi-agency working. I have developed new and important knowledge in relation to how practitioners from a wide range of agencies operationalise the Mental Capacity Act 2005 in relation to people who self-neglect.

The second way in which this thesis makes a significant original contribution to knowledge is through its contribution to methodology. This study makes a theoretical contribution by applying the methodology of AR in a new setting, that of multi-agency working within the public sector. It confirms and expands the existing AR methodology and introduces a novel variation, by its use of individual ‘change promises’ to contribute to change within the workplace and within individual practice. This variation is a useful addition to the methods available to the action researcher.

Both of these areas of contribution then foster a third dimension of contribution. When the subject matter of multi-agency working with people who self-neglect, was combined with the action research methodology, what emerged were rich insights into working practices and new and useful ways of understanding how practitioners could change and improve the ways they worked in concert to improve the lives of service users who self-neglected. New solutions were identified by participants which have begun to translate into practice.

9.3 Main conclusions

The main conclusions which emerged from the AR process are presented in summary, in relation to the four research objectives.

9.3.1 What are professional's roles and responsibilities in relation to self-neglect cases and how do the different professionals contribute to a joint understanding?

I found that professionals had a poor understanding of the job roles and responsibilities of others in self-neglect cases, and in the wider safeguarding arena. This was demonstrated both in my interviews and in the workshops. They were confused about the legal remit and boundaries within which other agencies worked, the timescales to which others had to adhere, and how other agencies could refuse to support a person with self-neglect issues who appeared to be in great need. Participants felt patronised and diminished when they perceived that other agencies did not give full credit to the way in which their profession and professionalism had developed over time.

My research showed that professional snobbery was seen as a barrier to multi-agency working. I found little sense of a coherent understanding of how all of the different agencies could complement each other in the work that they did and of making sure that the multi-agency 'puzzle' was something that could be understood by service users. However, I found that this lack of understanding of each other's roles went alongside a difficulty for practitioners, in many cases, of defining their own role in a self-neglect case. This was attributed to the blurring of professional roles in collaborative working, or the allocating of tasks that had previously been done by one group to other groups, so that roles had become very similar and difficult to distinguish from one another. The perception by community nurses of being required to take on aspects of the social work role were examples of this, and caused resentment and confusion.

Some agencies were actively seeking to move into the ‘territory’ of others, which could also lead to conflict and resentment.

9.3.2 Do professionals share a language around self-neglect?

Good communication in all of its dimensions was seen as extremely important but highly problematic, by practitioners in both my interviews and workshops. I identified that there was a lack of shared language about self-neglect, which hindered practitioners in trying to understand where each other was ‘coming from’. I was given many different explanations of why people might self-neglect. Unhelpful terms were used, such as ‘lifestyle choice’, which serve to frustrate and in some cases astonish other practitioners. Yet my research shows that the vocabulary which is available to practitioners is impoverished, when terms such as ‘squalor’ are only used with reluctance, or the issue of smell appears to lack terms for its articulation. This is compounded by the very different responses that self-neglect invokes in individuals. This is in relation to both their personal understanding of what causes people to self-neglect, and their own standards of cleanliness and hygiene. It is compounded by different views on when there is a moral and ethical duty to intervene. What one person sees as ‘clutter’ may be another person’s ‘squalor’, and there is no objective standard against which to measure this, or any agreement about whether this is even possible. These individual responses underlie professional and agency responses, which can lead to misunderstanding and conflict.

9.3.3 How do various professionals reach consensus in relation to self-neglect and how may different professional values conflict with each other?

I found that it was difficult for professionals to reach consensus about whether or how they should intervene in a self-neglect situation, in many instances driven by conflicting values and ethical perspectives. This led to high conflict situations, which were both task-based and value-based (Kim et al, 2016). I identified that personal fears and frustrations led to strategies for ‘covering your back’ such as providing excessive documentation. Inability to respond to a self-neglect situation because of factors such as lack of resources, skills or time led to behaviours such as ‘passing the buck’ which mitigated the worry, but then caused conflict with other agencies. I found various strategies used to deal with conflict but, in the main, I identified that practitioners were not concerned with conflict resolution, but with winning the ‘battle’, whatever the terms of engagement might be. My research found that a key area which caused conflict was the operationalising of the Mental Capacity Act 2005, which despite having been in force for more than a decade, I found to be poorly understood by some agencies, and believed to be misused in its application by others. Practitioners expressed vivid fears and anxieties to me about what would happen to them if they got something ‘wrong’ in a self-neglect case, particularly in relation to mental capacity.

9.3.4 What do professionals consider as important in achieving successful multi-agency working?

The fourth objective of my study was particularly informed by the AR approach. Following on from the interview phase, I developed the ‘Headlines’, which were a summary of the areas which practitioners had told me could or should be changed or modified to improve multi-agency working with people who self-neglected. Some of these areas were familiar from the existing research on multi-agency working, some were more specific to the local context, but all were taken forward by me to the multi-agency workshop phase of the research. Here participants looked at data from the first phase, analysing the relative importance and ‘do-ability’ of the ideas generated from the first phase. They prioritised actions and considered the way forward, both organisationally and individually.

The main priority for action identified by participants in all four of the workshops was the issue of improving all aspects of communication between the different agencies involved, and many excellent ideas were put forward by participants about how this could be done. Although the workshops were extremely successful in fostering multi-agency working, in practice it was evident to me that it was difficult for participants to commit their organisations to potentially time consuming, uncertain changes, which might bring them into conflict with other agencies, cause further duplication, and ultimately make more work for themselves. I found that a more successful approach was the carrying out of individual change which participants committed to, through making ‘change promises’ at the workshops, on which they reported back to me six weeks later. I could see from these that many participants had managed to bring about, or set in motion, changes in their workplace with systems and colleagues, changes in their work across agencies, changes in their work with service users, or changes within themselves.

9.4 Strengths of the study

9.4.1 A positive basis for the research

I was fortunate in that this study did not come from something going ‘wrong’ in the local context with multi-agency working. The study was not commissioned in response to a SAR or a local crisis, it grew from genuine interest, amongst practitioners and their employers, in exploring the area of self-neglect in relation to multi-agency working. This meant that the general mood of participants was buoyant and willing. I was also fortunate that such a wide range of agencies agreed to take part, and sustained their involvement throughout my research.

Reason & Bradbury (2008, p1) argue that it is through small-scale AR projects such as this that ‘people increase their ability to make sense of their world and act effectively’. With hindsight I can see that both my interviews and workshops enabled participants to simply sit and talk about their working world, a strength that should not be overlooked in an environment where otherwise they are continually measured and monitored in what they do. In my pilot study, the interviews, the workshops, and my subsequent research (discussed below), people have stressed to me the sense of empowerment and solidarity gained from listening to one another and sharing problems. Feedback from the workshops (chapter 7) also demonstrates this. Noga et al (2015) note that participants in their study gained in confidence and self-esteem as they began to feel less professionally isolated by sharing their concerns, and I witnessed this amongst my participants.

9.4.2 Action research and multi-agency working are a good 'fit'.

Watts & Jones (2000) argue that there are many commonalities between AR and multi-agency working, and describe a circular process whereby AR is used as a way of promoting and enhancing inter-professional practice and where multi-agency working can illuminate particular dimensions of AR. An example that I witnessed from this research was the success of the participatory workshops, but also the difficulty of moving the ideas for change that emerged from these into practise. Winter (1989) takes this further by arguing that AR can be seen as 'an idealised version' (p59) of professional practice. However, as someone who found the AR process very 'messy' (Cook, 1998; Thomas-Hughes, 2017) indeed, I would contend that both AR and multi-agency working can be very complex and complicated, and though many synergies may be uncovered, what results may be far from an 'idealised' version of either.

Winter (1989) argues that practitioner focused AR is a way to help practitioners retain control over their working lives, and I believe it can help allay some of Lazarrato's (2009) 'little fears', although 'little' ought, perhaps, to be dispensed with, as many of the fears which my participants expressed were very large indeed.

9.5 Limitations of the study

9.5.1 Which groups were not included?

Although my study overall involved participants from 15 different professional groups, there were still those who were excluded, and this could be seen as a limitation of the study. This study does not consider the perspective of the informal network of people who may support the self-neglecting service user. Families, friends, neighbours, faith organisations, local shops and so forth may all have a role to play, both positive and negative, in the lives of people who self-neglect and, in many cases, will work alongside formal services. My research had good reasons for looking specifically at people who are paid to provide services, but there would be much of interest in a study which explored these informal networks and their linkages with formal service provision.

Lastly, in terms of inclusion in the study, as shown in chapter 5, participants in the interview phase of study came predominantly from three groups – social workers, community nurses and housing officers. I felt this was a reasonably accurate reflection of the key professionals who would be most likely to be involved in self-neglect cases. However, although other professional groups participated, I would have liked greater representation from some, which I was unable to achieve at the time, despite trying. My consolation was that a good occupational distribution was achieved in the workshops. However, as I reflected in chapter 7, I perhaps did not give enough thought to grade delineations within professional groups, which, particularly as an outsider to most of the organisations in the study, I initially knew very little about.

Inevitably, there were one or two agencies which were missed out. I had wanted to include community pharmacists in the study, but was unable to recruit any within the timeframe, despite repeated attempts and trying different avenues. Probation services decided not to participate in the interview stage, feeling it was not relevant for them. However, probation officers did attend the workshops, and their contribution was very valuable, so it was regrettable that their voice had been missed initially. Similarly, it was difficult to recruit GP's for the interview phase (though some were recruited), but their representation at the workshops was much more substantial.

9.6 Recommendations for multi-agency working with people who self-neglect.

This research produced many recommendations from practitioners themselves about how multi-agency working with people who self-neglect might be improved. These were my 'Headlines', which have been discussed in Chapters 6, 7 and 8. These 'Headlines' emerged from the interview phase of my research, and were taken forward, explored, developed and refined by participants in the workshop phase of the research. However, as a result of my reflection on the research, I would add some further recommendations for multi-agency working to be developed successfully, specifically when working with people who self-neglect, though some of the recommendations may also apply more widely.

9.6.1 Recommendations for practice

- Ways to minimise the fear and reluctance surrounding the assessment of mental capacity need to be explored across all organisations where the MCA is relevant. All agencies have a role to play in putting the MCA into practice and this is not currently happening in the areas in which this research took place. Agencies need to accept their responsibilities to undertake or contribute to assessments. Although they would potentially open themselves up to more work in the short term, the gain would be that by being more proactive, they would place themselves in a stronger position to be able to challenge the assessments of others from a position of knowledge, which currently are a source of frustration. Alongside this, opportunities to carry out joint assessments should be encouraged so that this becomes routine, and joint accountability is accepted practice. The opportunity for practitioners to work alongside more experienced colleagues to conduct assessments (Willner et al, 2013) should be promoted.

- Agencies which are opting out of completing MCA assessments need to be challenged, at the LSAB level and above, rather than being tacitly allowed to adopt this position. Not only is it a huge source of conflict, as one participant correctly opined, having to get another professional in to do the assessment was a waste of resources and delays decision making, and it needs to be stopped.

- The complaint of 'not understanding what each other does', needs to be taken seriously by all agencies. Opportunities need to be provided for practitioners from different agencies to enable them to do this. A formal shadowing scheme which was linked to yearly appraisal and continuous professional development would be one option, for example.

- The knowledge, skills and experience of support staff who are working day-to-day with people who self-neglect, and often have the closest, most trusting relationships with them, need to be properly acknowledged within the multi-agency process. The uneasy position of private domiciliary care agencies in the multi-agency picture needs to be overcome and accepted by some other agencies, as their staff play a very important role in keeping many people who self-neglect in their own homes. The roles of home care staff, tenancy support workers, mental health support workers and so forth, in the lives of people who self-neglect are overlooked and undervalued, yet they often hold the key to successful outcomes for the service user.

- Agencies urgently need to explore ways in which the voice of the self-neglecting service user can be heard more strongly within the multi-agency forum. Professionals are very aware of the particular needs of people who self-neglect in relation to how best to contact them, who best to lead the approach, how to build a relationship, but the systems in the various agencies, particularly in relation to safeguarding, often seem to mitigate against that knowledge being used.

- Emphasise difference. Although this may sound counter-intuitive, many of the discussions I had with practitioners indicated that they were confused by the blurring of their roles and identity with other in the multi-agency picture. They had lost sight of what was special about the job that they did and this then had implications for their professional autonomy and confidence. It is possible that teamwork could be strengthened by practitioners having confidence about what they did that was unique to them and the values of their profession. It may be that the same would hold true of multi-agency working , if practitioners felt more confident about what they did that was distinct and gave them a specialism within the multi-agency setting. This could lead to reduced conflict with others.

- Improved standardised tools for assessment of the severity of self-neglect are urgently needed, to help practitioners reach shared conclusions.

- Although local authorities in England and Wales have to submit annual figures to the DoH detailing the numbers of safeguarding cases they have dealt with, they do not have to provide any demographic information within these figures. Thus it is not possible to know the breakdown of gender, ethnic origin or age of people who have been the subject of a S42 Care Act safeguarding enquiry due to self-neglect. The reason for this appears to be that the DoH do not wish to place further administrative burden on local authorities, but having this information would allow local authorities and their partner agencies to target their resources more accurately in the area of self-neglect.

9.6.2 Recommendations for education and training

- My research showed that there is a continued need, and thirst for, more discussion and learning on the MCA, which is itself an evolving piece of legislation as it is interpreted through case law. This is particularly true around issues of decisional and executive capacity which practitioners are increasingly being asked to explore (Braye et al, 2014b). However, this is not necessarily a need for training per se, but a need for the opportunity to discuss fears and confusion, to admit to uncertainty, in a non-threatening forum.

- Practitioners need to be helped to understand that where a person who self-neglects is deemed to have capacity, this does not mean that the person should be abandoned. Better education and training around the Human Rights Act 1998 would help to counter the apparent use of the MCA to permit non-intervention.

- Train practitioners in conflict resolution skills. In this research, practitioners described the different ways in which they dealt with conflict (see Chapter 6), but these generally fuelled the conflict rather than resolving it. Having some knowledge of what strategies help in resolving interpersonal conflict could be very helpful in this area.

On a positive note, many of the recommendations above, and contained in the Headlines, are low or no cost, but rather are about practitioners having honest conversations within their own organisations and externally, and questioning their own risk adversity.

9.6.2 Recommendations for further research

- More research is needed into multi-agency working between loose collaborative groups of professionals working in the community, who do not share budgets, employer or location, in relation to their work with particular service user/patient groups. Much of the emphasis in the literature is placed on integration of health and social care, but this tends to miss the wider picture of multi-agency working, which for many practitioners is much more the reality, particularly in the safeguarding of vulnerable adults and children. West & Lybonikova (2012) call these groups 'pseudo teams', but from my experience with this research I do not think they are even as strong as that, and might be more accurately referred to as pseudo collaborations or individual case collaborations.

- More research is needed on 'what works' in multi-agency working, and examples of success. Existing research is criticised for being small-scale and having limited applicability, but perhaps an acceptance that multi-agency working is very much a small-scale undertaking, with local constraints and characteristics, and will be very different according to the different needs of service used, could help move the focus away from trying to find the 'holy grail' (Glasby, 2017) of collaborative working. Perhaps there are instead many shards of the grail to be found, which are about what works, in a particular place, at a particular time, with a particular group of practitioners, for a particular group of service users. Putting that grail together might create a more useful vessel made of good practice.

- Further research on the experience of service users being on the 'receiving end' of multi-agency interventions is needed. There is a paucity of research in general on what service users feel about having multiple professionals involved in their care, and a focus on people who self-neglect, who are typically characterised as being fearful of and resistant to intervention, would be very valuable to inform collaborative service design and delivery. I have discussed in previous chapters the difficulties that have been encountered in researchers carrying out research with people who self-neglect, yet there is perhaps potential for involving practitioners more fully in carrying out such research, with a greater participatory emphasis.

- There is as yet very little research which explores the costs involved with self-neglect cases across the spectrum of agencies who work with people who self-neglect. This is possibly because these costs very much remain hidden as cases are passed from one agency to another. It would be extremely informative to compare the cost of the type of reactive care and support typically available for people who self-neglect when things go wrong (such as Paramedic and Police call-outs, A&E admissions, eviction proceedings, admission to residential care etc.) with the cost of providing proactive ongoing, low-level support services.

- The uncritical inclusion of the Clutter Image Rating (Frost et al, 2007, Appendix 1) into the self-neglect policies of many local authorities in England needs to be subjected to academic scrutiny. The tool is poorly validated with little evidence to support it being used in a UK context. Alongside this, other tools and frameworks could be explored.

9.7 Myself as a researcher

My journey through this research has been one characterised by change. Most of these changes have been extremely positive, but one or two have left me with unanswered questions.

Undertaking this research has taught me to take stock, to sit back, to reflect, to question my beliefs and actions, to analyse my situation reflexively. Why did I think a particular way? What led me to think that? In what other ways could I look at a situation? It has changed the way I see the world. Some of this is due to the impact of the ideas of social constructionism, which have allowed me to think about how my participants shaped their world together, and to see how social 'problems' such as self-neglect come into being. I have also been struck by the optimistic possibilities of social constructionism, in realising that a given belief or development does not have to be a particular way, it is simply how it has been socially constructed, and therefore the construction could be changed. However, doing this research has also made me angry. To sit and talk to practitioners who are trying very hard to do their best, under almost intolerable circumstances and with unreasonable demands being made of them, has filled me with rage and sadness.

Many practitioners from many professions told me how difficult it was for them to do their jobs in the way that they would wish and in the ways that they were trained to do. Older practitioners carried memories of when they believed times were better, and could not understand how it had come to this. The fear that people felt was tangible, yet was also a political choice – it did not have to be like that. I particularly felt, for many reasons, that the job community nurses were being asked to do was unsustainable and exploitative, and I was deeply grateful for the fact that they managed to find any time to talk to me. In the multi-agency puzzle, they are where the buck stops. They have no choice about providing a service to patients who need it and must respond quickly, they are drowning in paperwork and utterly deskilled, and because of the deep cuts their service has suffered over the past few years, there simply are not enough of them (Maybin et al, 2016). I interviewed nurses who I can only describe as being in a state of despair. I cannot understand why the imminent collapse of this service does not receive much greater attention.

On a more practical level, doing AR, particularly the workshops, has changed the way I teach students and train practitioners, something which I could never have anticipated. Through the ideas of Mackewn (2008) I learned to be more comfortable with creative and more uncertain approaches. When I work with a group of people now, I think much more about Mackewn's idea of the choreography of energy which I had been dismissive of at first. When I was struggling with the group interviews, discovering the concept of proxemics enabled me to understand why I might be finding situations difficult, rather than blaming myself for feeling that I wasn't doing a very good job.

I am required to deliver training to practitioners as part of my job, but I now have doubts about the worth of 'training' as a concept. Many practitioners I spoke to seemed to long for the magical 'training' which was going to tell them everything they needed to know about mental capacity, or self-neglect, or whatever, and allow them to deal with every problem they encountered. What they needed much more was to build confidence in their own phronēsis, to re-connect with their practice and practical wisdom, which, I came to believe, had been crushed and devalued by the demands upon them. As I was nearing the end of this research, I had to take some time out to deliver training to senior staff in a local authority. I realised this was actually a ridiculous idea. I could not 'train' them to do something, as if they were performing seals, and I was in some way cleverer or superior to them. They knew much more than I did, as an outsider, about what the reality of their job was. But what we could do was work together, share ideas, contribute from our different perspectives and learn from each other. This is much more exciting than 'training'.

The ways I understand the political drive towards agencies working together has also changed. Prior to undertaking the research I think I had seen collaborative working as a fairly benign but unquestioned concept, which was in some sense 'logical'. I now see it as something very different than that. Something with a very weak research evidence base in terms of its benefits for service users (who, the research shows, generally don't seem to mind who delivers the service so long as the service gets delivered). Something which promises financial savings, but doesn't deliver. Something which disguises budgets cuts and austerity, yet manages to throw the blame on practitioners. SAR's are a good example of this – if things go wrong, it is seen as being because people and agencies haven't worked together properly, not because of massive cuts to public services, not because of huge increases in levels of poverty and deprivation for service users and carers. I believe that the working together agenda has been uncritically accepted, and needs to be radically re-interrogated.

The way I conceptualised responses to self-neglect also changed. The more I read about self-neglect, the more I felt that so much of the literature that set out to discover 'why' people self-neglect was pointless. If somebody had the time to sit down and talk to a self-neglecting person, and get to know them, they would probably find out 'why', if indeed, finding out why is even that important. I found myself with a troubling thought. If some people who self-neglect are finding themselves subject to the Foucauldian gaze, because they have been constructed as a social problem and they are not playing the neo liberal game, what then was I doing, trying to help agencies to work together better, in order to further oppress the self-neglecting people?

As I read and thought more about the way in which neoliberalisation has insinuated itself into the public sphere and specifically the impact it has had on AR (Greenwood, 2012; Jordan and Kapoor, 2016; Anderson, 2017), I also began to wonder whether I wasn't simply being a lackey of neo-liberalisation, trying to make NPM reforms and changes more palatable for my participants through using an AR approach. By encouraging them to try to change the way they worked together, wasn't I placing the onus (and blame) on them, and absolving the wider political forces that had put them in this position?

I have not satisfactorily resolved these questions for myself, but I am heartened by Anderson (2017) who argues that AR has the 'potential to disrupt NPM and open up authentic and democratic spaces in which to engage in inquiry' (p432). That is what I have done in this research.

9.8 Further developments

Stringer (2014) argues that good AR projects often have no well-defined ending. Instead, 'new realities emerge that extend the process of enquiry. Problems merge, submerge, or become incorporated into larger projects.' (p207). That has been the case with this research project. I discussed in the previous chapter how, whilst my research was taking place, four local authorities in the region combined their LSAB's. Serendipitously, the new Board wanted to do some further work around the issue of self-neglect and safeguarding, and wanted to work with me, to use some of the key issues from my research, in further work. The result of this was that over the course of 2018, we held three further multi-agency, participatory workshops for staff from the four boroughs involved. I co-facilitated these, with the Head of Safeguarding from one of the local authorities. This was a point where I felt I could really use my reflections from the previous cycles of the AR better to plan what we did. For example, I felt that in the initial interview phase, I had not put enough emphasis on what was going right, what people did well together. Therefore, in co-designing the 4 borough workshop, I tried to have as a starting point valuing the practice wisdom of the participants and looking at what practitioners were getting right.

During the workshops, we explored some of the issues that had come out of the interviews and previous workshops, such as lack of understanding of each other's roles. We worked on teasing out the differences in the language that was used to describe self-neglect – what was the difference between 'collecting' and 'clutter', 'hoarding' and 'squalor'? We also spent time considering how to improve outcomes for people who self-neglect, specifically in relation to continuity of support, as the importance of building a trusting relationship had been raised many times by participants in my study. We explored whether it would be possible, in certain complex, high risk self-neglect cases, for the cases to remain open long-term to a member of the multi-agency team who might be involved with the self-neglecting person. We also discussed how understanding of the MCA could be improved amongst practitioners.

The outcome of these workshops was two-fold. Firstly, we co-produced a 'Short Guide to Working with Complex Self-Neglect Cases'. This was written and edited by the participants themselves, and the aim was to capture a 'bottom up' perspective on working with self-neglect, rather than impose 'top down' policy (see p.*v* for a copy of the Guide). A local Hoarder's Support Group were consulted on their views about the Guide, and these were included also. The Guide has been made available to all staff in the agencies which sit on the Boards, via websites and hard copies. It is hoped to roll it out to other authorities in the region, and there has been a great deal of interest. Lauder et al (2005c) had found that developing inter-agency guidelines was an 'especially difficult exercise' (p318) because of the range of agencies who might be involved in self-neglect cases, so this was a terrific achievement.

The second outcome was a significant change in the process for working with people who self-neglect. Each of the four boroughs agreed that they would adopt a policy of keeping complex self-neglect cases open, for a long period of time if it was warranted, to allow the practitioner involved to build up a trusting relationship with the self-neglecting person. These cases, when identified, will sit outside the normal timescales for safeguarding cases. The Guide includes what the criteria for such cases might be, although it is not prescriptive.

Stringer (2014) discusses the importance of celebrating significant accomplishments in AR projects. We have recently held a launch event for the Guide and the changed process. The next task is to consider how the change around keeping cases open can be evaluated, in terms of the difference it makes to practitioners, to caseloads, to budgets, and most importantly, to service users themselves. That is the key outcome.

I cannot claim all the credit for these developments. I have been very lucky in that people who were involved in the early stages of my research, both participants and allies, have 'stuck with it' as it developed, and have now used their positions to push forward changes to practice in a way that I, as an outsider researcher, could not. I was also fortunate that a more senior manager from one local authority became involved, who was able to push forward changes suggested by practitioners at the Board level. However, I do feel that as an action researcher, I was the catalyst for these developments, and that the work I undertook helped practitioners to feel more confident about their roles, and what they brought to their work with people who self-neglect, which has ultimately resulted in these changes. It has been a fascinating journey for me so far, and I hope it continues.

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Appendices

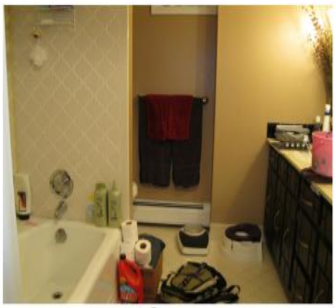
Appendix 1: Clutter Image Rating

(Extract, From: Frost RO, Steketee G, Tolin DF, Renaud S. Development and validation of the Clutter Image Rating. Journal of Psychopathology and Behavioral Assessment. 2008; 32, 401–417).

Clutter Image Rating Scale: Bathroom

Please select the photo below that most accurately reflects the amount of clutter in your room

1



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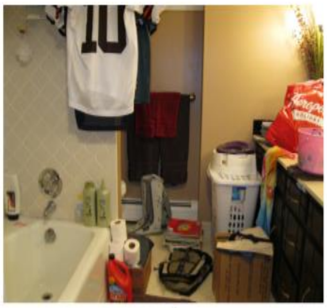

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Clutter Image Rating Scale: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room


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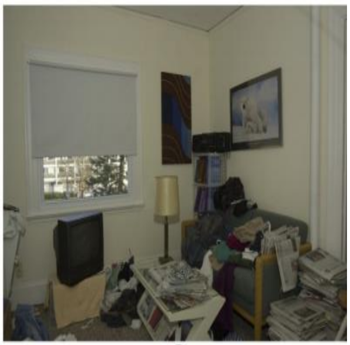
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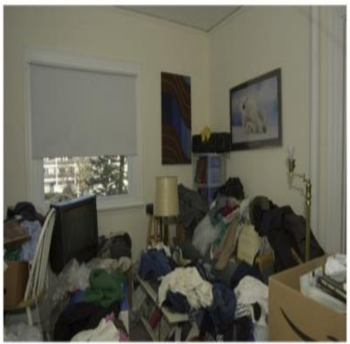
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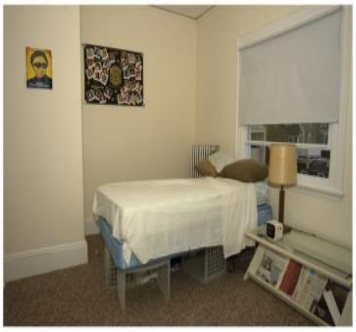
Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room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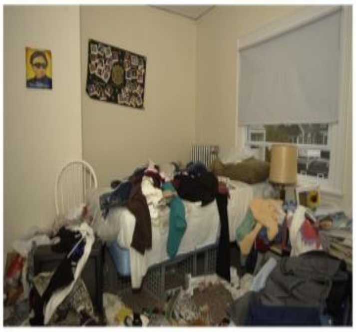
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Appendix 2: Action Research Typology (adapted from Hart and Bond, 1995, Table 3.1, pp 40-43)

Consensus model of society
Rational social management

Conflict model of society
Structural change

Action research type	Experimental	Organizational	Professionalising	Empowering
Educative base			Reflective practice Enhancing professional control and individual's ability to control work situation Empowering professional groups; advocacy on behalf of patients/clients Practitioner focused	
Problem focus			Problem defined by professional group; some negotiation with users Problem emerges from professional practice/experience Contested professionally determined definitions of success	
Improvement and involvement			Towards improvement in practice defined by professionals and on behalf of service users	

Appendix 3: Components of Trustworthiness in Qualitative Research

(Adapted from: Lincoln & Guba, 1985; Lincoln, 1995; Schwandt, Lincoln & Guba, 2007; Shenton, 2014: White, 2014)

Trustworthiness	
Component	Demonstrated by?
Credibility: How congruent are the findings with reality?	• Prolonged engagement • Persistent observation • The adoption of well-established research methods • The development of an early familiarity with the culture of participating organisations • Random sampling of individuals to serve as informants • Triangulation (of sources, methods, investigators or theories) • Tactics to help ensure honesty in informants when contributing data. • Iterative questioning (return to matters previously raised) • Negative case analysis • Frequent debriefing sessions • Peer scrutiny of the research project • The researchers reflective commentary • Background, qualifications and experience of the investigator. • Member checks. • Examination of previous research findings
Transferability: Can we apply these findings to other contexts or with other groups of people?	• Thick description of the phenomenon under scrutiny • Providing the boundaries of the study: a) the number of organisations taking part in the study and where they are based; b) any restrictions in the type of people who contributed data; c) the number of participants involved in the fieldwork; d) the data collection methods that were employed; e) the number and length of the data collection sessions; f) the time period over which the data was collected.
Confirmability: ensuring as far as possible that the work's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher' (Shenton, 2004)	• Triangulation • The extent to which the researcher admits their own predispositions • Reflective commentary • Recognition of shortcomings in study's methods and their potential effects • In-depth methodological description to allow integrity of research results to be scrutinised • Audit trail – data oriented approach, and a theoretical audit trail
Dependability	In-depth description of: • The research design and its implementation • The operational detail of data gathering • Reflective appraisal of the project • Use of overlapping methods NB. Lincoln & Guba (1985) argue there are close ties between dependability and credibility.

Appendix 4: Components of Authenticity in Qualitative Research

(Adapted from: Guba & Lincoln, 1989; Lincoln & Guba, 2003; Lay & Papadopoulos, 2007; Schwandt, Lincoln & Guba, 2007; Bryman, 2016)

Authenticity	
Component	Demonstrated by?
Fairness	‘the extent to which different constructions and their underlying value structures are solicited and honoured within the evaluation process’ (G&L, 1989: 245) 2 step process: • Ascertaining and presentation of different value and belief systems represented by conflict over issues. Exploration of values when clear conflict is evident should be part of the data-gathering and data-analysis processes • Negotiation of recommendations and subsequent actions with stakeholding groups. (Schwandt, Lincoln & Guba, 2007)
Ontological authenticity	Does the research help members to arrive at a better understanding of their social milieu? (Bryman, 2016, p386)
Educative authenticity	Does the research help members to appreciate better the perspectives of other members of their social setting? (ibid) Did participants come to better understand and appreciate (though not necessarily agree with?) each other’s way of thinking and acting? (Schwandt, Lincoln & Guba 2007)
Catalytic authenticity	Has the research acted as an impetus to engage in action to change their circumstances? (Bryman, 2016, p386) As a result of [participation in the research] have we actually begun to act differently? (Schwandt. Lincoln & Guba, 2007)
Tactical authenticity	Has the research empowered members to take steps necessary for engaging in action? (Bryman, 2016, p386)

Appendix 5: Visual examples of proxemic challenges

Obviously I could not take photos in situ, but needed to find a way of representing the groups and my difficulties. I have therefore used toy figures to depict group interview participants. In the pictures that follow, although it appears that figures are sat on the floor, they were sat on chairs, so please imply a chair. I wanted to emphasise where there were empty chairs in the space. I am the figure with the blonde hair and the clipboard.

Group 1

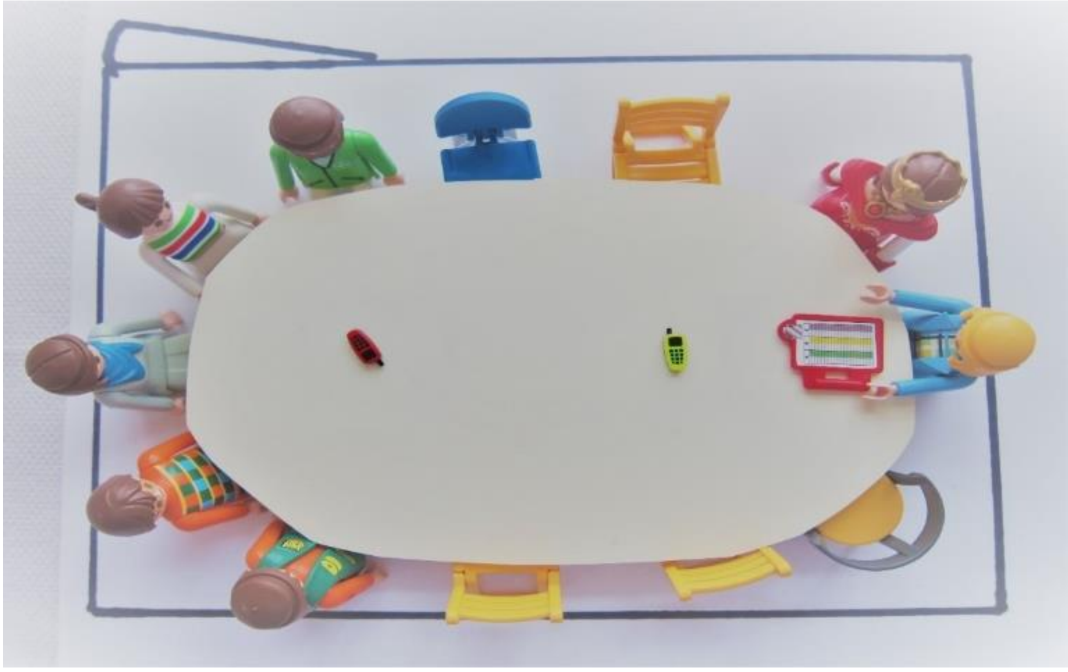
This was the room where this team regularly held their team meetings. Owing to the size of the table, it was very difficult for all of the team to fit in. Although I would have preferred not to be at the head of the table, and always tried to avoid this where I could, the team were already seated when I arrived, so I had no choice. Similarly, the team manager (indicated by the figure in the crown) sat next to me, again as often happened. This potentially made it harder for people to speak honestly, as we would both be making eye contact with them.

As the picture shows, a couple of people were 'outliers' as they could not fit at the table. I came to learn that this was a very powerful position (one replicated in some other groups) as they could withhold their involvement unseen by other members of the team, but seen by me. In Hall's (1966) terms, people sat in my intimate space, my personal space and my social space, which mitigated strongly against me being able to feel comfortable.

Group 1 Close up

This picture shows in more detail the problems for me as facilitator. Both the manager and the man on my right were in my intimate space, an uncomfortable gender issue for me (Sorokowska et al, 2017). It was an extremely hot day, and I could smell them both. As Sorokowska et al (2017) note, ‘the possibility of increased visual, tactile, auditory, and olfactory stimulation is enhanced at closer distances’ (p579). I could also feel the heat coming from their bodies. The seating meant that they could read my questions, and I felt unable to make any notes because they would be able to read these also. They were too close for me to be able to make natural eye contact.

Group 2



In this example, I was shown to my seat by the team manager, who then sat next to me. As other members of the team came in to the room, they chose to sit at the further end of the table. I assumed more people would join to fill the empty seats, but they did not. I was forced to move between intimate space, when speaking and listening to the manager, who spoke very quietly, and far social space when speaking or listening to the rest of the team. This was an extremely difficult situation to manage.

Group 3

I was in a very privileged space here, in the heart of their professional lives. However, it was a very difficult group to run. As shown, people were in my intimate, personal and social space. The person sat behind me was extremely close to me, yet I could not make eye contact with her without turning away from the rest of the team. The door was behind me, so people could not leave or enter unobtrusively. The 'outliers' here could simply turn from the group conversation to their computer screens if they became disinterested, and though their colleagues in front of them couldn't see, I could. I felt that people used their desks as shields against me, the invader.

Appendix 6: Question schedule

Can you tell me your first name, your job title, and roughly how many years' experience you have?

1. What is your team's role and responsibility in a self-neglect case?
2. What other professionals might your team typically work with in a self-neglect case?
3. How well do you think your team and other professionals that you might work with understand each other's roles and responsibilities in self-neglect cases?
4. Do you think different professionals have different definitions of what 'self-neglect' is?
5. How tolerant of self-neglect do you think other professionals groups are compared to you?
6. Tell me about the role of mental capacity in working with people who self-neglect.
7. How do you decide who is best to deal with a particular concern?
8. How do you all agree about what is the best thing to do?
9. How would you constructively challenge a decision by another professional that you didn't agree with?
10. Tell me about how information sharing works between your team and other teams.
11. What works well in multi-agency working in self-neglect cases?
12. Do you think there is anything that could be changed in the way people work together, which would improve outcomes for service users/patients who are self-neglecting?
13. Is there anything else that anyone feels we should have mentioned?

Appendix 7: Invitation flyer for workshop, LA1

Self-neglect and multi-agency working – what can we learn and what can we change?

Half-day participatory workshop

This workshop is for practitioners from all agencies who might be involved in working with people who self-neglect and will be facilitated jointly by AB, Public Health consultant; CD, Clinical Lead Complex Care; and Elaine Aspinwall-Roberts, researcher from Liverpool John Moores University.

The aim of the workshop is to bring together recent learning and research on self-neglect in the [LA1] area. Elaine has been running focus groups and interviews with many different teams throughout [LA1] over the last few months, to identify how practitioners felt multi-agency working could be changed to improve outcomes for people who self-neglect. More than 100 staff have participated, from 12 different professional groups. CD has recently conducted a Practice Learning Review focused on a self-neglect case in which many different agencies were involved.

This workshop will provide feedback from both the research and the review.

Workshop programme:

- The changes that people identified (research findings) – how can we put these into action?
- A case for change? Looking at the chronology and story of a recent 'live' case, from a whole system point of view, to explore what works well, and where the 'pinch points' are that could be better.
- Mental Capacity and self-neglect: the 'wicked' issue.

Please come to the workshop willing to share ideas, be open to challenge and keen to contribute! We hope that the workshop will give you a chance to have an honest discussion with colleagues from other agencies, to look at ways of improving the way that we all work with people who self-neglect. At the end of the workshop, we hope to have a plan for putting some changes into action.

Dates, times and venues:

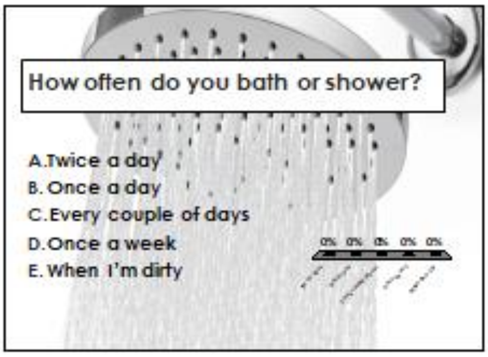
There are 30 places available at each workshop, and they are open to any agency

Please RSVP to:

Appendix 8: Ice Breaker Quiz

'CLEANLINESS IS NEXT TO GODLINESS'

How clean are you?



How often do you bath or shower?

A. Twice a day
B. Once a day
C. Every couple of days
D. Once a week
E. When I'm dirty

How often do you wash your hair?

A. Every day
B. Every couple of days
C. Every week
D. When it looks dirty

How often do you wash your hands after going to the toilet?

A. Always
B. Usually
C. Sometimes
D. Never

How often do you change your bedlinen?

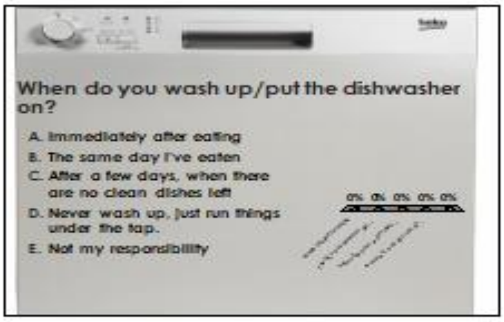
A. Daily
B. Weekly
C. Monthly
D. When it looks dirty
E. Not my responsibility

How often do you hoover?

A. Daily
B. Every couple of days
C. Weekly
D. Monthly
E. When I can't see the pattern of the carpet any more
F. Not my responsibility

How often do you clean the toilet?

A. Daily
B. Every couple of days
C. Weekly
D. Monthly
E. When it looks dirty
F. Not my responsibility



When do you wash up/put the dishwasher on?

A. Immediately after eating
B. The same day I've eaten
C. After a few days, when there are no clean dishes left
D. Never wash up, just run things under the tap.
E. Not my responsibility

Do you eat food that is past its 'use by' date

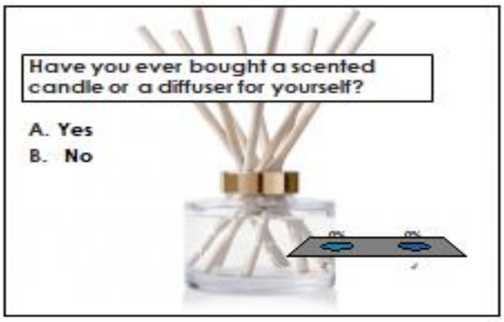
A. Never, always throw it away
B. Probably, if it still looks and smells ok
C. Yes, would scrape off the mould and eat it

Do you wear deodorant every day?

A. Yes
B. No

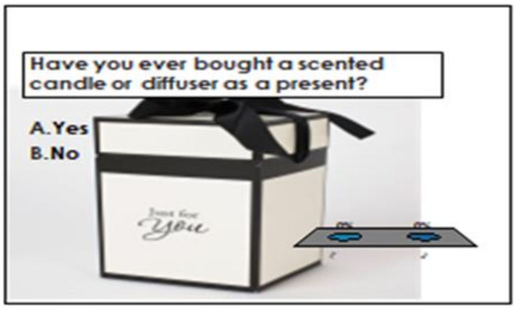
How often do you wear perfume or after shave?

A. Every day
B. Most days
C. Sometimes
D. Never



Have you ever bought a scented candle or a diffuser for yourself?

A. Yes
B. No



Have you ever bought a scented candle or diffuser as a present?

A. Yes
B. No