

Reflections on engaging with an advisory network in the context of a 'sensitive' research study

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1 **Reflections on engaging with an advisory network in the context of a ‘sensitive’ research** 2 **study**

3

4 **Background**

5 Introduction

6 In the last twenty years, involving non-academic stakeholders in research has moved from
7 being a specialist to mainstream practice in health and social research (World Health
8 Organization, 2015; INVOLVE, 2015; Coulter, 2011). There are often overlapping reasons
9 for involving participants in research and approaches vary in emphasis and degree depending
10 on the disciplinary context as well as the skills and outlook of the research team involved
11 (Cornwall, 2008). In broad terms, however, working in a collaborative, respectful and
12 inclusive way with people who use research and/ or are ‘experts by experience’ has become a
13 cornerstone of ‘best practice’, particularly in applied health research (Brett et al., 2014).
14 Involving different types of people in shaping decisions about how and what knowledge is
15 developed, opens up a previously restricted area of professional practice to wider public
16 scrutiny and influence. In turn, it is argued, new types of knowledge and understanding may
17 be developed which better represent and address the needs and experiences of people who
18 may otherwise be overlooked or marginalised (Aldridge, 2016; Nind, 2014).

19

20 The different degrees of involvement have been conceptualised as a ‘ladder’ with the
21 implication being that there are better or ‘stronger’ forms of involvement (Arnstein 1967).
22 However, what is best for a particular project is contingent on the context and focus of the
23 study. Thus, it is perhaps more helpful to think in terms of a continuum of involvement as
24 judgements concerning what is the ‘best’ approach can be problematic (Nind, 2014). In this

1 paper, forms of involvement are regarded as being at various points along a continuum in
2 terms of amount and type of involvement, rather than categorised as ‘better’ or ‘worst’.

3

4 In the contemporary literature, there is limited reporting about why and how researchers
5 choose some forms of involvement and collaboration over others. This paucity in reporting is
6 particularly noticeable in the case of involvement that is time or activity-limited. Yet, this is
7 the most common type of involvement work and it is influential in shaping research
8 questions, designs and outcomes (Mathie et al, 2014). Therefore, by making visible what this
9 type of work ‘looks like’ – and being prepared to address the questions this raises about its
10 value and role – knowledge and practice can be shared and developed. The aim of this paper
11 is to identify, reflect on, and critically consider how, why and with what implications our
12 work with an advisory network, as a form of participant involvement, played out. In view of
13 the limited guidance and lack of evidence about the role and operationalisation of advisory
14 fora – despite their prevalence and popularity – we considered it timely to contribute to a
15 critical conversation about their strengths and limitations. The intention is that the issues
16 addressed will resonate with a range researchers and stakeholders working together to
17 improve the value and impact of health and social care research.

18

19 Advisory fora

20 Advisory groups are generally fora in which people with different interests and experiences
21 come together as a means of ensuring the research is conducted in accordance with best
22 practice guidelines and is managed efficiently. They are also referred to as steering or
23 stakeholder groups. When convened specifically as a forum to advise on participant
24 involvement in research, common activities include: providing feedback about the credibility
25 of a research question, contributing to design and development decisions, and, critically

1 reviewing ethical issues and procedures to promote participant welfare. Across a range of
2 disciplines, advisory groups are a common way of including people in research; nevertheless,
3 there has been little critical discussion of their role (Mathie et al, 2014) beyond some notable
4 examples in the field of children’s research (McCarry, 2012; Moore, Noble-Carr &
5 McArthur, 2016) and adult learning disability research (Porter, Parsons & Robertson, 2006;
6 Lewis et al, 2008). These authors report mainly positive experiences working with advisors.
7 In particular, the authors highlight the intellectual and methodological contribution advisors
8 made to their studies (Moor, Noble-Carr & McArthur, 2016; Lewis et al, 2008). However,
9 they also caution that more attention needs to be paid to the potential ethical complexities and
10 practical issues of working with advisors, particularly when advisors have communication
11 problems and/or additional social needs (Parsons et al, 2006; McGarry, 2012).

12

13 Because advisors are not involved directly with decision-making with research collaborators,
14 they do not have significant responsibilities or ownership of the research data and outcomes
15 (Nind, 2014). Instead, advisors are understood to ‘influence’ decisions made by the research
16 team. Moreover, although research proposals often indicate that an advisory group will work
17 with the team, the work they do is rarely subject to ethical or regulatory review. This
18 indicates that advisory work is implicitly conceptualised as ‘outside’ or ‘additional to’ the
19 research process (Goberman-Hill, 2014). For several reasons, then, the work of advisory
20 fora is often obscured from institutional and peer scrutiny (Mathie et al, 2014). This paucity
21 of critical attention seems at odds with the investment and attention now directed towards
22 more conventional forms of participatory and collaborative research practice. In the
23 remainder of the paper the process of establishing and coordinating an advisory network for a
24 ‘sensitive’ project is explored to address this deficit. However to set this discussion in
25 context, it is first necessary to consider the nature of sensitive research.

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Sensitive research and the inclusive agenda

Sensitive research is an umbrella term for studies that investigate emotive topics that are often personal in nature (Dempsey, Dowling, Larkin, & Murphy, 2016). Common examples include research on death, abuse, intimate relationships and sexuality. These topics can be difficult to talk about because of their complexity or because of social and historical norms about the permissibility and capacity of people to share their experiences, particularly if they are considered atypical or taboo (Dickson-Swift, Kippen, & Liamputtong, 2007). In seeking to make visible hidden experiences and to explain complex, often troubling social situations and individual circumstances, there is often an association between sensitive research and research about and with people who may be ‘vulnerable’ or marginalised (Serrant-Green, 2011). Much sensitive research is underpinned by an ethical and intellectual commitment to develop new forms of knowledge that challenge traditional ways of knowing and exercising power, thereby giving credence to marginalised experiences and enabling hidden issues to be better heard and seen (Mantoura & Potvin, 2013; Bradbury-Jones & Taylor, 2015). Nevertheless, the term ‘sensitive’ should be used cautiously, taking into account the contextual and subjective understandings of what is (and is not) complex, important and contentious about an issue amongst the people whom the research is for or about (Powell, et al, 2018).

It is perhaps unsurprising that there is a close association between sensitive research and more ‘radical’ forms of involvement and collaboration. Broadly, ‘stronger’ or ‘radical’ participatory approaches conceptualise the experiential knowledge and subjective insights of lay people as equivalent, and sometimes more important than, knowledge developed by scientific or theoretical methods (Beresford, 2000). The central, if not the only, purpose of

1 the research is to develop knowledge that is driven by and useful to, stakeholders (sometimes
2 called co-researchers or experts by experience). Thus, such approaches are intended to
3 redress (to some degree) the inherent power asymmetry between academic and non-academic
4 researchers in the design and conduct of research. Participatory approaches also emphasise
5 carrying out research *with*, rather than *by* or *for*, a group. One example is action research: the
6 development of knowledge by members of a community about issues that are important to
7 them and who benefit from carrying out research, either by developing skills and/or effecting
8 practical change (Fals Boreda, 2001). Another example is co-production research, where
9 different stakeholders from different groups or communities collaboratively develop
10 knowledge to address shared and clear objectives (Ramierz, 1999; Hewison, Gale & Shapiro,
11 2012). Broadly, then, participatory and co-production research seek to support, and
12 sometimes empower, co-researchers to express their views and to have an equal role in
13 decision-making pertaining to the aims and outcomes of research (Catalani & Minkler, 2010;
14 Conrad, 2004 and Israel, Schulz, Parker & Becker, 2001).

15
16 Nevertheless, as the research community has developed more experience of involving
17 participants in research, an informed, critical, agenda to improve it has also emerged. This is
18 particularly the case in areas of sensitive research where ethical and methodological
19 considerations are closely intertwined. For example, Bourke (2009) argues that it is overly
20 simplistic to assume that power can be meaningfully recalibrated only by sharing or
21 devolving research tasks or processes. These seemingly benign practices may obscure wider
22 power inequalities in terms of who benefits from and owns the knowledge produced by
23 research. This raises further, potentially uncomfortable questions about how appropriate and
24 meaningful some participatory projects are for those involved (McCarry, 2012). Moreover, it
25 challenges us to consider how much their rapid rise is underpinned by a political and cultural

1 requirement to appear ‘authentic’ rather than being methodologically coherent and responsive
2 to the needs and objectives of participants and co-researchers (Gristy, 2015). In response,
3 there have been calls to re-examine the ethical and methodological rationale of participatory
4 and collaborative research. Nind (2014) for example, challenges the assertion that ‘more
5 radical’ approaches are ‘more ethical’ and encourages researchers to consider whether other
6 forms of participation are as, or more appropriate. Nind (2014) also suggests that practices
7 along the involvement continuum have different strengths and limitations and that it is
8 incumbent on researchers to think critically and carefully about their use on a case-by-case
9 basis.

10

11 The aim of this paper is to share and critically explore our experience of working with an
12 advisory network in the conduct of a ‘sensitive’ research project. In the following sections,
13 we discuss: 1) How the network evolved as a result of ethical and pragmatic choices. 2)
14 Potential issues when discussing sensitive issues ‘outside’ of the participatory or participant
15 context and, 3) Practical and epistemic issues involved in (not) ‘taking’ advice.

16

17 **The advisory network**

18 Context

19 For the past three years we have been conducting a qualitative study investigating the
20 experience of family carers affected by abusive, violent, or, harmful behaviour by the older
21 person for whom they care. In planning this project, we wanted to ensure the needs and
22 views of people with personal insight about caring and/ or family violence were central to our
23 decisions about the scope and purpose of the study. Given the under-developed empirical
24 and theoretical landscape and the challenges involved in researching this sensitive issue
25 (Isham, Hewison & Bradbury-Jones, 2017), their experiential knowledge of caring and/ or

1 family violence was, we considered, both valuable and necessary to inform our empirical
2 study. In view of this, we established an advisory network to work with during the design
3 and initial development of the study. In reporting our experience of working with advisors,
4 we aim to make transparent our practices and to contribute to a wider discussion about the
5 design, development and conduct of advisory fora. We set out the central characteristics of
6 what we mean by the term ‘advisory network’ in Text Box 1.

7

8 **Insert Text Box 1**

9

10 Establishing the network

11 To recruit advisors, we posted information about the project on a national, health service user
12 involvement research database (www.invo.org.uk) as well as on our project website. We also
13 shared information about the advisory roles with carers’ organisations, health service user
14 networks, advocacy organisations and non-specialist community and voluntary agencies. The
15 aim of these combined strategies was to increase the number and range of potential advisors
16 reached. However, we had not realised fully how reluctant caring organisations would be to
17 share our recruitment materials in any face-to-face forum and/ or for us to talk directly with
18 prospective advisors. Many services were concerned about the potential sensitivity of raising
19 the issue of harmful behaviour with carers and their family members. Some service
20 representatives reported that harmful behaviour and/ or domestic abuse was not ‘within the
21 remit’ of their service and therefore the issue never came up in their work with clients. Other
22 services highlighted that this was a ‘safeguarding issue’ that could (and perhaps in their view
23 should) be a matter only for social services. When services did agree to share information
24 about the project, they emphasised the importance of doing so discreetly. They chose, for

1 example, to distribute recruitment materials by email or website postings, rather than putting
2 up posters or taking up our offers to speak at meetings and general events.

3

4 Over the course of a six-month period, eight people became actively involved in the network.
5 Six advisors identified themselves as carers or ex-carers, one advisor identified herself as
6 needing and receiving care and one advisor worked as a professional in older people's health
7 services. There were six women and two men in the network. We communicated with
8 advisors on a one-to-one basis, by telephone, email, video-call and sometimes by meeting in
9 person. The members of the network did not meet all together at any point. In terms of
10 recording our actions, we made detailed notes of conversations and compiled a reflective
11 diary about interactions and work with network members. Work with the network was also
12 discussed regularly at project meetings. The network played an active role in terms of our
13 recruitment work, suggesting amendments to materials and questioning decisions about the
14 project's chronology and methodology. The members also helped to create a reflective space
15 to discuss the purpose, justification, and conduct of the research project.

16

17 **1. A pragmatic or an ethical choice? Working with advisors as part of a network**

18 From the outset, the research team emphasised the potentially anonymous and clearly
19 confidential nature of taking part in the project and many advisors took the decision to use
20 telephone and virtual communication as their methods of choice for liaising with one another
21 and the academic members of the team. Advisors may have felt that non-direct contact (e.g.
22 email and phone calls) afforded time and space to consider how and when they engaged and
23 that this in turn this may have increased feelings of confidence and comfort when
24 communicating with us. In addition, for many people, it was not possible to travel or to
25 commit time to attend face-to-face meetings regularly. This was due to many advisors'

1 significant and ongoing caring commitments for family members. These advisors reported
2 that the flexible, asynchronous nature of online communication, coupled with the ability to
3 set up (and rearrange) when, how often, and in what way they communicated with the
4 research team was a helpful aspect of working in a network. Given that caring for people
5 with fluctuating, complex needs is demanding of time, emotional energy and is uncertain and
6 stressful we decided that it was essential to facilitate practical ways of taking part in the
7 project that took account of these pressures on carers (Horrell, 2015). Underpinned by
8 principles of cooperation and partnership, it seemed axiomatic that advisors needed to have a
9 meaningful degree of choice and control in how they worked with us. In addition, because
10 advisors were located across the country (in part due to online recruitment) this raised
11 challenges for us as a small research team in terms of setting up face-to-face meetings, as
12 used in the more conventional advisory 'group' model. Similarly, although we offered to
13 remunerate advisors for any expenses they incurred (e.g. for travelling), this was not a
14 sufficient measure in and of itself to address the time commitment needed to attend such
15 meetings. Thus it became clear that coordinating an advisory network could be an
16 appropriate, and perhaps even necessary, way of working with advisors.

17

18 Reflecting on the initial development of the network, we recognise that there are considerable
19 advantages of drawing on more direct forms of engagement – such as holding group
20 discussions or group exercises – in fostering creativity, critical dialogue and co-production of
21 joint work. Indeed, these are all advantages identified by other researchers working with
22 advisory groups (Lewis, 2008; Porter et al, 2006; Moore et al, 2016). When researching
23 topics of considerable social or emotional complexity, group-work may confer additional,
24 strengths in the advisory context. For example, providing the time and social space to develop
25 working relationships – between advisors and the research team – that support the discussion

1 of ‘difficult’ issues (Robinson, 1999). The group environment can also facilitate the co-
2 identification of latent meanings that touch on personal and experiential knowledge that may
3 be difficult to discuss explicitly because of feelings of anxiety or embarrassment in the case
4 of seemingly taboo or emotive issues. These strengths are well-recognised in the context of
5 focus groups exploring sensitive issues (Bradbury-Jones, Taylor & Herber, 2014; Brondani,
6 MacEntee, Bryant & O’Neill, 2008). With all this in mind it is relevant to ask if, in using a
7 network rather than a group approach, we forfeited an opportunity to develop ‘deeper’
8 discussions that may have enabled us to better identify the emotional and social needs of
9 advisors. Certainly, we faced time and resource limitations that inhibited our ability to build
10 the relationships that can support and empower *some* people to take part in ‘sensitive’
11 research (Dickson-Swift, Kippen & Liamputtong, 2007) and for *some* potential ‘gatekeepers’
12 to build trust in us as an ‘outsider’ research team (Clark, 2011). Nevertheless, our network
13 evolved in response to the needs, preferences and social situations of carers who wanted to,
14 and were willing to take part, in this study. As Aldridge (2014) suggests, social research with
15 vulnerable groups – that explores issues of social sensitivity or complexity – evokes ethical
16 issues by “default and design”. Thus, there was a balance to be struck between adapting the
17 way we sought and listened to advice – to promote inclusiveness and increase the comfort
18 and control of advisors and participating organisations – without resorting to surface or
19 tokenistic engagement that would undermine the ethical and intellectual rationale of the
20 project.

21

22 **2. Discussing sensitive issues ‘outside’ of the context of the advisory network**

23 Because our research topic evoked potentially uncomfortable and emotive questions, it was
24 important to take time to unravel (and re-consider) the words and concepts we were using to
25 talk about carers’ needs and experiences with our advisors. We also needed to make clear

1 why we were seeking to explore the lived experience (and subjective meanings) of carers
2 affected by harmful behaviour and to assuage concerns that we were seeking to hold either
3 carers, or the older person for whom they cared, responsible for any violence, abuse or
4 distress that had taken place. To ensure there was clarity about the responsibilities of the
5 research team, we spoke with advisors about this issue several times and provided
6 comprehensive written and electronic information about the project's aims and scope, and
7 their role.

8

9 In terms of their input, some advisors focused on the technical and specific issues of research
10 ethics and others were more concerned with issues of harm, violence, and caring. Those who
11 offered valuable insights on both areas perhaps unsurprisingly tended to be more active
12 members of the network, working with the research team more directly. However, several
13 advisors shared historic personal experiences of violent and abusive behaviour and/ or
14 witnessing difficult and distressing behaviour on the part of close family or friends. The
15 advisors concerned shared this information with the research team openly and unprompted at
16 an early stage. Echoing research about the motivations of participants in sensitive research
17 projects, advisors said that they were taking part in the study *because* of these experiences,
18 motivated by their concern that there was limited recognition of, and support for affected
19 families (Clark, 2010; Appollis et al. 2015). We were surprised by the candid and personal
20 nature of these accounts and we are grateful to advisors for the emotional risk they took in
21 talking with us. Nevertheless, we were cognisant of our role, informing advisors about the
22 likely outcomes and limitations of the research process, a point discussed in more detail
23 below.

24

1 For some people, it is possible that taking part in the advisory network was preferable to
2 becoming a research participant. Indeed, advisors may have been protecting themselves from
3 being in a socially or emotionally vulnerable position by limiting the way they talked about
4 their personal experiences (Gabb, 2010). However, although advisors had initiated these
5 discussions willingly, we were mindful that talking about sensitive and personal topics had
6 the potential to trigger negative emotions and that advisors may not have anticipated the
7 impact of this (Newton, 2017). Working with research participants, there is an expectation
8 that researchers inform people of the potential benefits and risks of taking part and check
9 their understanding: indeed, this is integral to the process of obtaining and maintaining
10 participants' consent (Wiles, Crow, Heath, & Charles, 2008). Moreover, there is an
11 expectation that researchers can anticipate and address the risks of disclosure and respond to
12 emotional and behavioural cues to minimise unnecessary distress or discomfort (Appollis,
13 Lund, de Vries, & Matthews, 2015). Yet there is no clear guidance for how such issues
14 should be managed with advisors. In our project, we sought to recognise and support
15 advisors' welfare needs, when appropriate, by drawing on skills in reflective listening and
16 attention to non-verbal cues and emotion-focused communication. We also regularly
17 discussed any concerns about advisors' needs and the nature of their involvement in project
18 meetings.

19

20 Reflecting on how advisors sought to share, disclose and sometimes limit how and what they
21 talked about in relation to harmful behaviour, we could perhaps have anticipated that some
22 people would share personal experiences. Indeed, it seems credible to suggest that the lack of
23 formal guidance or reporting about advisors' potential welfare needs reflects that most
24 researchers – particularly those who have expertise researching sensitive or complex social
25 issues – manage these issues subtly and intuitively. They draw, in effect, on their knowledge

1 and skills working with participants. It may therefore seem unnecessarily prescriptive,
2 perhaps even pedantic, to call into question whether there is a need for critical and practical
3 guidance for researchers working with advisors.

4

5 Nevertheless, this lack of attention reflects the wider point that because the work of advisory
6 fora is infrequently recorded or analysed, it is afforded less practical and symbolic value. In
7 addition, there is likely to be a wide range of researchers – from novice to expert, and, from a
8 range of social and health-related disciplines – who are working with advisors as part of
9 sensitive research projects. In the contemporary literature, it is difficult to assess what the
10 advisory fora landscape is, or the frequency and complexity of ethical or welfare issues that
11 arise when working in such spaces. In turn, this makes it difficult to ascertain how
12 researchers go about identifying and supporting advisors and the degree to which this work
13 overlaps with the more visible and formalised practices of working with research participants
14 or co-advisors, particularly those with complex or additional needs. Relying on researcher’s
15 integrity and ‘intuition’ may mean that advisors do not always benefit from the same level of
16 protection and support that other people in the research process are afforded.

17

18 **3. Taking advice: managing different views and interpretations**

19 We wanted advisors to express their views and ideas, particularly if they differed from our
20 own. Indeed, it was of great practical and intellectual benefit to the research team to have the
21 time to discuss and consider the project with advisors. Their contribution was vital in
22 challenging our thinking and informing practical amendments to the project. Advisors also
23 surfaced critical questions about our proposed approach to engaging with participants, as well
24 as some of our latent assumptions about carers’ understanding of issues such as
25 confidentiality and anonymity. For example, advisors emphasised that people would be

1 discouraged from taking part if there was a perceived risk that their participation might lead
2 to the involvement of statutory health or social care services in their life. Although we had
3 considered this issue, we had not anticipated the degree to which the prospect of intervention
4 by statutory services - and the threat of having a loved one 'removed' from the family home –
5 would be an ethical and practical issue. Cognisant of this pressing concern, we took time to
6 explore and explain the rationale and limitations of confidentiality within the interview space
7 with advisors and to communicate this clearly in our participant-focused literature.

8

9 Advisors also challenged the research team's aptitude to assess participants' suitability for the
10 project and the level of follow-up support available for participants if they experienced
11 negative effects after taking part in an interview. In fact, on the matter of participant welfare,
12 the advisors scrutinised our proposals in more detail than the formal research ethics review
13 panel. We believe advisors' experiential knowledge, combined with their proxy role as an
14 advocate, conferred a degree of symbolic capital and prescience on their advice, particularly
15 in matters of participants' welfare (Locock, Boylan, Snow & Staniszewska, 2016). Rightly
16 or wrongly, many advisors identified themselves as either being similar to, or able to talk for,
17 potential participants: in short, they identified themselves as part of a social group or
18 community, however displaced and tentative, of family carers or people who knew about the
19 needs of family carers. This highlights how concepts of 'vulnerability', 'and 'being
20 marginalised' can be shaped in a range of research spaces (Aldridge, 2014). In turn, it may
21 be helpful for researchers to consider how they will seek to capture, and potentially manage,
22 different types of contribution – be they foregrounded in experiential, subjective or empirical
23 understanding – on such matters (Bray & McDonnell, 2012).

24

1 There were some differences of opinion between the research team and advisors about the
2 focus and impact of the project. This raised questions about how we could best identify and
3 address the expectations and needs of network members. For example, several advisors
4 rejected the suggestion that older people who were unwell could be abusive or harmful in
5 their behaviour. These advisors suggested that the project's focus should be on investigating
6 the causes of carer breakdown and stress and, in particular, focus on how inadequate or
7 inappropriate support from health and social care services was the 'real' issue at hand, not
8 harmful behaviour by the individual older person. In addition, some advisors told us that
9 they wanted to have the 'truth' told and to speak up for other carers in light of their own
10 negative and distressing experiences with health and social care services. We became
11 concerned that some advisors had unrealistic expectations about what the project could
12 achieve and that this was the motivation for their involvement in the project. This was at
13 odds with our own more modest expectations about the study's likely impact. To address this,
14 we had discussions with advisors about the probable outcomes of the project. This involved
15 being open about the fact that the impact of research on practice and policy is often more
16 limited than the public assume and researchers would like it to be (Nicolini, Powell, Conville,
17 & Martinez-Solano, 2008). We learned from this that clear discussion of objectives at an
18 early stage of the project may have played a more central part in developing a shared agenda
19 for working with advisors, including explanation of the type and nature of knowledge being
20 developed.

21

22 We acknowledge it could be questioned how confident advisors felt to challenge us on key
23 issues in the study, given our role (and power) as 'professional' researchers (Porter, et al.,
24 2006; Aldridge, 2016). Indeed however much we sought to address this in our interactions
25 with advisors and our commitment to partnership working, we recognise that these inter-

1 personal dynamics are relatively superficial in terms of recalibrating decision-making power
2 and ownership of research outcomes (Karnieli-Miller, Strier & Pessach, 2009). If anything,
3 the asymmetry between symbolic and decision-making power is particularly significant in
4 advisory group fora given that there is no formal expectation that the work of the network
5 will be shared and reported on publically. We also accept that some of these tensions touched
6 on fundamental differences about what knowledge is and what is valuable to know – i.e. they
7 had an epistemic dimension. How to reconcile these issues is a long-held and important area
8 of debate in co-production and involvement research, particularly when working with
9 ‘vulnerable’ or marginalised populations (Bray & McDonnell, 2012). It overlaps with
10 questions about who ‘owns’ and influences the outcomes of research, and the attendant power
11 dynamics such distinctions or partnerships can engender. However, such philosophical and
12 ethical issues are another under-explored dimension of debate and reporting on advisory fora.
13 A summary of the key learning points developed form working with an advisory network in a
14 ‘sensitive’ research project, are summarised below in text box 2.

15

16 **Insert Text Box 2**

17

18 **Discussion**

19 Although sensitive research is generally aligned with more ‘radical’ forms of participatory
20 and collaborative practice, advisory fora – and, specifically advisory networks - offer a useful
21 and sometimes more appropriate form of inclusion and engagement for some advisors and for
22 some types of research study. This is not to suggest that advisory networks are a more
23 appropriate way of soliciting feedback and evoking discussion than advisory groups, or any
24 other form of involvement practice. Rather, we suggest that advisory networks offer an
25 alternative approach that can be used alone or in conjunction with other mechanisms for

1 feedback, fieldwork, and co-produced activities. They are one way of facilitating participant
2 involvement.

3

4 When investigating ‘sensitive’ issues and working with vulnerable or marginalised groups,
5 carving out meaningful opportunities to reflect, learn and collaborate is of practical, ethical
6 and conceptual value. It takes time to build sufficient trust to foster relationships between
7 researchers, individuals and groups, particularly if these interactions and encounters are
8 shaped by structural imbalances in social power and status. It was our experience that
9 working with advisors using a network approach offered some helpful ways of addressing
10 these issues. For example, the asynchronous nature of communication between researchers
11 and advisors made it possible for a range of people from different social backgrounds to
12 participate in the research project. In turn, this created opportunities for personal disclosures
13 and reflective discussions. Moreover, the iterative nature of exchange between the research
14 team and advisors was a catalyst for practical and conceptual adjustments to the project. This
15 helped ensure the research team and advisors were able to develop new ways of collaborating
16 in the design and development of the study. The network approach may also provide a
17 practical way to carve out confidential, less formal, spaces in which people feel more
18 comfortable to contribute to sensitive, often ‘hidden’, research topics.

19

20 In addition, when investigating under-explored social phenomena, researchers need to remain
21 open to nuance and detail: to idiosyncratic themes and ideas that may, when integrated with
22 other information and theory, have interpretive meaning. Taking time to notice and attend to
23 small, often subtle details about how people talk and understand an issue, as well as to step
24 back and notice what is not said or expressed, can help to identify some of the ways that
25 sensitive issues become or remain hidden. In turn, this means that researchers may need to

1 tolerate uncertainty to make more informed methodological, design, and analytical decisions
2 that better reflect and attend to the complexities of the phenomena under investigation. In
3 short, field work, collaborative discussion and exploratory design work tends to take longer
4 but can be valuable in shaping the aims and agenda of the resulting research study (Vaswani,
5 2018). Working with advisors in a network forum can create useful opportunities for this type
6 of respectfully curious work. In addition, it was our experience that some relationships and
7 interactions between researchers and advisors developed over time. As discussed above, these
8 shifting roles raised some ethical questions, however they also underscored the different
9 types of advice that people ‘gave’ and the need for us as a research team to adopt different
10 ways of ‘taking’ their contributions on board. This underlines how context-specific advisory
11 roles are depending on the nature of the research project (Cornwall, 2008). It also highlights
12 the importance of researchers carefully considering their approach (including their
13 conceptualisation of advice as knowledge) when establishing and reporting on work with
14 advisory fora in a sensitive research context.

15

16 In spite of the benefits, there are several limitations of the advisory network approach. As
17 discussed already, it is questionable whether non-direct communication methods are adequate
18 – when used alone – to foster a relational and emotional context that fosters ‘deep’ discussion
19 of sensitive issues, albeit with a focus on research design. In addition, primarily working in
20 the context of one-to-one exchanges reduces opportunities for advisors to engage in collective
21 discussion that may be more organic, socially stimulating and potentially affirming or
22 empowering. These are important ethical considerations, particularly when considering the
23 needs of people who are in some way ‘vulnerable’ or marginalised from some forms of social
24 participation and inclusion. Researchers therefore need to be cognisant of the balance to be
25 struck between affording confidentiality and responsiveness to advisors (based on their

1 preferences and wish for anonymity) with that of creating a disjointed and solitary experience
2 for them. One way of addressing this is to establish mechanisms for both individual and
3 group contact from the outset of the network's work. Because our early efforts were focussed
4 on recruiting advisors to work in ways that were acceptable to them, we gave less attention to
5 establishing mechanisms for group interaction. In addition and on a practical point, because
6 our network relied on online, telephone and video-call communication methods, it is likely to
7 have excluded people without the means or inclination to use these technologies. In turn, this
8 may have implicitly compounded age and educational biases about who takes part in and who
9 shapes research. Although there has been a considerable shift in access to and familiarity
10 with these particular communication methods – that may, for example, foster greater
11 opportunity for advisory networks than a decade ago – the needs of potential advisors must
12 always be the key factor determining which approaches are used.

13

14 Perhaps one of the most important considerations about the future relevance and development
15 of the advisory network approach is whether researchers (and advisors) can begin to shift the
16 cultural expectations about what is considered valuable and worthy of reporting. This will be
17 difficult to achieve if the development and presentation of empirical and theoretical findings
18 remains the main element of research that is reported (Gooberman-Hill, 2014; Gillard, 2012).
19 This serves to obscure the contribution of those involved in the work and the under-reported
20 and 'hidden' realm of work of advisory fora. Moreover, these limitations restrict the impact
21 of research on sensitive or complex social issues, for the reasons outlined above.

22

23 **Conclusion and limitations**

24 There were limitations and problems working with an advisory network and we hope that by
25 sharing our experiences and reflections as a group of researchers, then other people will be

1 able to build on our learning (see Text Box 2). The network played a central role in shaping
2 our research project and we wanted to acknowledge the contribution of its members whilst
3 maintaining their anonymity in accordance with assurances given. We recognise that by
4 sharing researchers' experiences of one network and one study, the recommendations we put
5 forward are tentative. Moreover, the relevance of the network approach will vary from study
6 to study, depending on the research question and population from which the advisory network
7 is drawn. We welcome further innovation of the advisory network approach and critical
8 commentary about its methodological and ethical implications. We suggest that advisory
9 networks are a practical and useful way of working with people to develop research
10 knowledge. Their dynamism and flexibility provide opportunities for different, more
11 iterative, types of exchange and influence between advisors and researchers in the course of a
12 project. This brokering of different forms of communication is the central characteristic of
13 all types of involvement and we are not advocating that advisory networks supersede, or are
14 incompatible with, other forms of advisory fora or participatory practice. However, we think
15 that the network approach is of particular relevance and value to advisors and researchers
16 exploring complex social phenomena. It is one of a range of approaches on the continuum,
17 referred to earlier, that can be used to good effect in areas of sensitive research.

18

19 For advisory groups and networks to be better acknowledged and more critically developed,
20 researchers need to make time and space to think about how they describe, share, and,
21 conceptualise their work. We echo the recent recommendation that there needs to be more
22 consistent and critical reporting of participatory and collaborative research (Staniszewska, et
23 al. 2017), and the role of advisory fora. As a result, we hope that this paper will encourage
24 discussion about what researchers and advisors are doing, what is working well and what
25 needs further practical and conceptual development in this field. These are necessary ethical

- 1 and methodological dialogues pertinent to researchers from a wide range of disciplines.
- 2 Moreover, they are relevant to anyone who is interested in, and committed to, engaging
- 3 people affected by complex and sensitive social issues to lead, co-design and shape (research)
- 4 questions and outcomes that can engender positive and practical changes.

1 **Acknowledgments**

2 We acknowledge the contribution of all members of the advisory network and warmly thank
3 them for the time, energy, and the considerable intellectual and personal investment they
4 have made in the project and the development of this paper. Indeed the motivation to submit
5 this paper arose from a concern about how best to acknowledge the advisors' input and to
6 reflect on how we could better improve and support the work of such groups and networks in
7 the future. This acknowledgement does not include them as 'co-authors' in order to maintain
8 assurances about anonymity.

1 **Text box 1: Central characteristics of an advisory group network**

2

Summary of central characteristics
<ul style="list-style-type: none">• Communication between advisors and the research team is asynchronous and flexible, according to the needs of each advisor.• The network may ‘meet’ using tele-conferencing or online fora. The research team may also anonymously share feedback between advisory members and facilitate contact between members.• Because most communication takes place between the research team and advisors, it may be easier to include new members at different points in the research project.• Advisors provide advice and/or share experiences in a private and confidential space. Researchers are responsible for identifying and recording points of consensus and difference.• Depending on the research team’s recruitment strategy and advisors’ access to communication technology, advisors may come from a wide geographical area.

3

1 **Text box 2: Key learning points: advisory networks in the context of ‘sensitive’ research**

2

Summary of key learning points

- Advisory networks provide a flexible and appropriate space to discuss ethical or socially sensitive topics because communication with the research team is private and confidential. Critically, advisors can determine the nature and degree of their involvement with the research team. This may lead to additional or alternative forms of involvement in the wider project, as relationships between advisors and researchers develop over time.
- Advisory networks provide a means for people who cannot, or choose not to, take part in more direct and formal advisory fora to shape research design and development. This may lead to new insights and increased sensitivity to the needs of people who may benefit from, or be affected by, research on ‘hidden’ or ‘sensitive’ topics.
- If advisory networks do not include any face-to-face communication, it is questionable how appropriate they are for the discussion of ‘deeper’ (emotionally or ethically sensitive) topics. Depending on the individuals involved, they may also limit advisors’ opportunities for learning and social inclusion. These are important considerations in the context of research with marginalised or ‘vulnerable’ groups.

3

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