PROJECT TITLE: Researching public health interventions: scoping models and theories of disability

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1. BACKGROUND

1.1. Existing research and public health need

Nearly ten million people in England experience significant difficulty with day-to-day activities linked to long-term conditions, a population that includes those with lifelong and later-life conditions (Family Resources Survey, 2012). As ageing is associated with functional decline, this means that nearly half of those living with impairments are aged 60 or over (Banks et al., 2010) Many disabled people are also living with other physical conditions, such as coronary heart disease, diabetes and respiratory conditions (Family Resources Survey, 2012).

There are marked social gradients in disability across the lifecourse, with evidence of enduring effects associated with poorer childhood circumstances (Graham, 2005; Emerson et al., 2006; Birnie et al., 2011; Marmot and Bell, 2012). In addition and at each lifecourse stage, people with disabilities are disproportionately exposed to the social factors that contribute to health inequalities, including proximal risk factors such as smoking, obesity and lack of physical activity (Rimmer, 2011; WHO, 2011) alongside broader determinants associated with educational and employment opportunities, poverty and poor housing, and inequitable access to services (Emerson et al., 2012; Marmot and Bell, 2012). These environmental disadvantages are, in turn, disabling and create further barriers to social inclusion (WHO, 2011).

There is growing appreciation of the diversity of disabling experiences, with different impairments having their own aetiologies and trajectories, acquired in a wide range of circumstances, and mediated by individual, social and political contexts (WHO, 2011). The public face of impairment is also challenging previous perceptions by encouraging a more encompassing understanding of ‘being disabled’ (see Atkin et al., 2010). For example, although socially patterned, disability can affect anyone, including those with pre-existing chronic conditions, mental health problems and intellectual and cognitive impairments (Collins et al., 2011; Halfon et al., 2012; Marmot, 2012; Marmot and Bell, 2012). Moreover, international understandings have moved away from a strictly medical definition, where ‘disability’ is ‘caused’ by functional deficits (e.g. physical injury or intellectual disability), to one sensitive to environmental determinants and in tune with how people experience disability as they go about their day-to-day lives (Lollar and Crews, 2003).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) reflects this, such that disability is understood to result ‘from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’ (UN, 2007). Human rights and equality frameworks are also increasingly employed to articulate the moral claims and service needs of people with disabilities (WHO, 2012; Oliver and Barnes, 2012, Berghs, 2013), in order to reflect impairment complexity (Gridley et al., 2013). The CRPD, for example, sets out an international framework for citizen's rights and State obligations on health care provision, rehabilitation, accessibility and research with and for disabled people (UN, 2007). The UK is a signatory to this framework, which is further supported at a national level by the Equality Act (2010) which makes discrimination on the basis of disability illegal, while also requiring an equality duty in health care provision (https://www.gov.uk/equality-act-2010-guidance).

Public health interventions have a critical role to play in advancing the status and wellbeing of people with disabilities. Interventions to tackle underlying causes of ill-health and reduce health inequalities have the potential to transform their lives (Banks et al., 2008); such interventions also support wider policy objectives to promote independent living and care at or close to home (Department of Health, 2010). However, there are significant challenges to developing the evidence-base to inform such interventions.

This is because, to date, public health research has largely overlooked the experience of disabled people and been slow to accommodate shifts in understandings of - and the politics around – disability (Oliver, 1998; Bickenbach, 2012). For example, entry criteria for intervention studies can be set in ways that exclude people with impairments (Meyers and Andresen, 2000; Loeb and Eide, 2006; Krahn et al., 2009; Molden and Tøssebro, 2012) despite equity being an increasingly salient feature of public health interventions (Purdam et al., 2008). Perspectives and assumptions can be outmoded and inappropriate, with disability represented as a 'burden' to the individual and a 'cost' to society (Murray and Lopez, 1997; Andresen et al., 2000; Andresen and Meyers, 2000). There is also limited evidence on the types of public health interventions likely to be effective (Salmon et al., 2012).

Addressing these gaps is further hampered by the limited public health literature on intervention design, methods, including economic evaluation, and strategies to actively make mainstream disability-sensitive research by adapting universal and inclusive designs (Centre for Applied Special Technology, 2011; Williams et al., 2011; Feldman, et al., 2013). There is also little debate about how best to actively engage disabled adults, young people and children, particularly when trying to identify interventions consistent with disabled people's preferences (Dye et al., 2007; Nind, 2008; Feldman et al., 2012). There are then the further difficulties of accommodating the differences generated by lifelong, acquired or fluctuating conditions, where experience is further mediated by socio-demographic factors such as gender, social class, ethnicity, sexuality and age (Rimmer and Rowland, 2008; McDonald, 2012; Beresford, 2013; Williams et al., 2013).

It is these gaps that the NIHR call is seeking to fill. It is a challenging brief. Nonetheless, there are important platforms from disability studies and allied perspectives on which to build which, by offering alternative ways of defining and engaging with disability, can improve future interventions research (Mont and Mitchell, 2008; Loeb and Altman, 2007; Palmer and Harvey, 2012; Thomas, 2012). However, these perspectives typically derive from a different epistemological and ontological starting point to that informing mainstream public health research and policy (Barnes et al., 1999; Priestley, 2003; Thomas, 2007; Goodley, 2010;). Aligned to social and political movements of people with disabilities, disability is understood both as part of the wider structures of social inequality and as a human rights issue (WHO, 2011; Oliver and Barnes 2011; Barnes and Oliver, 2012). Research perspectives and methods that have built on this are grounded in an appreciation that disability is – and is experienced as – a dynamic interplay between impairment, attitudes and the environment (Barnes and Mercer, 2010).

Such approaches have generated a rich literature on models of disability, including ones developed by the WHO that accommodate social, relational, ecological, economic and medical models (WHO, 2011; Thomas, 2012). Recent international reviews, for example, have examined the application of different theories to public health interventions in terms of measurement, applicability and standardisation (Ustan et al., 2003; Madans et al., 2011; Palmer and Harley, 2012). Some reviews have also examined how public health theories could connect to disability measurements (Ravesloot et al., 2011). There are then studies assessing the relevance of public health outcome measurements to the experience of people with a disability (Andresen et al., 2000; Hays et al., 2002; Brazier et al., 2003; Mont and Mitchell 2008; Versteegh et al., 2012). Other work, although oriented to specific forms of impairments or groups, such as intellectual disabilities or mental illness or younger populations explores how disability impacts on and is affected by public health interventions (Harrison, 2006; Tennant et al., 2007; Rimmer et al., 2010), including health information (McConkey, 2006), health promotion interventions (Seekins et al., 2008), health checks (Robertson et al., 2010), self-management (Marks and Allegrante, 2005), personalisation (Sims and Cabrita Gulyurtlu, 2013), self-advocacy (Anatao et al., 2013) and access to health care (Alborz et al., 2005; Balogh et al., 2008); thereby providing insight into inclusive research strategies (Mactavish et al. 2000; Crawford et al., 2002; Cargo and Mercer, 2008; Catalani and Minkler, 2010).

While a rich resource, this disparate literature have yet to be synthesised in a way that makes it accessible to those commissioning and undertaking public health research. There have been few reviews providing advice on how to mainstream ‘disability’ when doing public health research (WHO, 2011), a major issue given that studies tend to exclude people with disabilities and rarely reflect the diverse range of circumstances in which disability is experienced (Feldman et al., 2012).

2.2 Benefits of the research

Public health interventions aim to improve population health and reduce inequalities. People with disabilities are at particular risk of poor health and are disproportionately disadvantaged vis-à-vis the social factors that contribute to health inequalities. While people with disabilities constitute a major recipient group for public health interventions, research has not engaged in any systematic way with the experiences of people with disabilities (Dale et al., 2012). This undermines public health’s ability to promote equity and social inclusion (Purdam et al., 2008). An appreciation of how different models of disability can inform the development and evaluation of public health interventions, together with the provision of guidelines on the most appropriate ways to incorporate the perspectives and experiences of those with disabilities, could achieve a step-change in research and policy (Reinhardt et al., 2013). It can help connect evidence-based practice to the diverse needs of those with disabilities, while also being sensitive to broader concerns about social disadvantage, accessibility and inclusion.

There are particular advantages of integrating current public health research to emerging ideas that see those with disabilities as active citizens, part of wider social networks (such as partners and parents) and as stakeholders in the services they use (Beresford, 2007 & 2013). Incorporating such perspectives, while maintaining a commitment to understanding what - and how - interventions work, can lead to a range of public health benefits (Nilsen et al., 2006). These include the promotion of health, social inclusion and equality and the potential for Government savings that improvements to the welfare of people with disabilities may bring.

The project will, therefore, (i) scope models and theories of disability and (ii) assess their implications for public health interventions. These two components of the NIHR brief will be addressed through two linked reviews. As well as a review of models and theories, we will review a sample of systematic reviews of public health interventions to assess how far current intervention designs incorporate approaches consistent with disability models and theories – and where major changes and/or minor adaptations would be required. This second 'benchmarking' review will ensure we provide NIHR with good practice guidelines for commissioning, grounded in an appreciation of current research practice, thus maximising the benefits of research.

2.3 Rationale for current study

The NIHR PHR Programme established the need for this research. Public health interventions have been a key feature of successive Government's policies, with a focus on developing interventions that both improve overall population health and reduce health inequalities. This drive has occurred against the backdrop of an ageing and increasingly diverse disabled population, and a cost-saving agenda that places a premium on people with impairments remaining in the community and accessing - and remaining - in the labour market, supported by effective health and social care interventions.

Increasing attention is being given to understanding how public health can deliver appropriate models of care and ensure better outcomes for disabled people, in which their rights are respected (The Marmot Review, 2010). The Department of Health, for example, began a partnership with the Disability Rights Commission (now part of the Equality and Human Rights Commission) to 'improve information and services, communications and levels of awareness of disability issues' (Disability Rights Commission, 2006; The King's Fund, 2011; WHO, 2011.) Such strategies promote the inclusion of disabled people, their rights and needs in all public services (Stein et al., 2009).

The complex and nuanced nature of disability, however, is rarely considered in public health debates, especially when evaluating interventions. With a large and growing proportion of disabled people, the UK needs a strong evidence base on which to build future intervention research; and one that specifically offers advice on how to reconcile established research designs with those informed by more inclusive models. Without this, we will continue to know little about what will work, for whom and under what circumstances.

The project will therefore review models and theories of disability and assess their implications for public health interventions. As well as a synthesis of literature on models and theories, the outputs from the project will include accessible decision aides for those who commission public health research, covering terminology/categorisation; study design and outcome measures; the incorporation of lifecourse perspectives; and public and patient and broader stakeholder involvement. This will enable commissioners to assess the likelihood that a commissioned research project will produce evidence relevant to the experiences of those with disabilities.

2. RESEARCH OBJECTIVES

Our aim is to carry out a two-stage scoping review to identify, assess and explain the implications of different models and theories of disability for researching the effectiveness of public health interventions; and to identify factors that will enable future research studies to engage with a broad and diverse range of impairment types and groups, in a way consistent with social equality and inclusion. We will address public health interventions of two types: public health interventions targeted at people with disabilities, which will enable us to explore the potential of more inclusive designs; and broader public health interventions potentially relevant to the lives of disabled people, in order to gain insights into the ability of mainstream research to capture the experience of disability.

In line with the commissioning brief, the research questions are:

1. How can different models and theories of disability appropriately inform research into the effectiveness of public health interventions? And to what extent can intervention research be sensitised to accommodate different configurations of diversity within and among general and disabled populations?
2. How do different models of disability map on to current research on public health interventions?
3. What are the implications for commissioning research into public health interventions inclusive of, or for disabled people in a way that accommodates appropriate terminology and measurement, which takes account of different causes and types of impairment, while being sensitive to the experience and needs of different demographic groups associated with gender, social economic position, ethnicity, sexuality and age?
4. How should participants, public and stakeholders be involved in research and what does inclusive research practice look like?
5. What study designs and relevant outcomes best capture the experience of impairment and disability in a way that maximises health benefits and ensures mainstream research reflects the experiences of people with disabilities?

Stage one includes a scoping review and synthesis of research discussing and critiquing models, definitions and theories of disability. This review will identify the range of models and theories (including strengths and possible limitations in generating inclusive approaches and capturing diverse experiences); their place within the field of disability studies and within the social and political movements of disabled people; and their potential contribution to mainstream public health research and policy. The review will explicitly focus on the questions highlighted in the commissioning brief, concerning the use of appropriate terminology and categorisation of disability; how best to reflect life course approaches when researching disability; facilitating stakeholder involvement in disability-focused research; and adapting inclusive and sensitive study designs and outcomes.

Stage two includes a review of purposively-selected public health reviews from the Cochrane (international) Library of Intervention Reviews (CIRs). Thirty CIRs will be where people with disabilities are identified as a key target group. Thirty will be reviews of more generic interventions, which have potential relevance to people with disabilities. A selection of reviews – also purposively sampled - will then be subject to more detailed analysis to ensure our analysis reflects diversity. This material will be supplemented by purposively sampling relevant databases held by the Campbell collaboration and Joanne Briggs Institute to ensure our analysis captures a diverse a range of disabilities and research approaches as possible; while generating insights from reviews yet to be published. By building on the stage one review and applying its critical insights to assess the perspectives and methods employed when evaluating interventions, we will focus on: mapping the models and theories of disability underpinning the intervention and research; the terminology and categorisation of disability used or if no discussion, a consideration of the intervention's relevance to the experience of disabled people; whether and how a lifecourse perspective is incorporated, methods of participant, public and stakeholder involvement; and the extent to which study designs and outcomes (including economic evaluation) capture the diverse range of experiences associated with being disabled.

The research will produce a review and synthesis of research relating to disability models and theories, a benchmarking report on current practice in intervention research and an evidence-based and critically informed guide for research commissioners, assessing and evaluating the consequences of adapting a more nuanced and socially inclusive approach to disability when undertaking mainstream and targeted intervention studies. Such a guide will enable commissioners to judge the likelihood that research on a particular intervention will apply to a range of different disabilities, as experienced in different social contexts.

3. RESEARCH DESIGN

Our proposed two-stage review will provide an overview of current theoretical and empirical debates, including examples of best practice, from which successful public health interventions can be developed. First, we will undertake a scoping review and synthesis of research critiquing different models and theories of disability. Second, we will use the premier international source of effectiveness reviews - the Cochrane Library of Intervention Reviews – to purposively identify and review public health interventions in which people with disabilities are either a key target group or where more generic interventions have the potential to improve outcomes for people with disabilities. We will build on the first review, applying its critical insights to assess the perspectives and methods employed in the second. Appendix A provides a flow chart, summarising our approach.

4.1 Stage one: Using the literature to scope different models of disability

Stage one, a scoping review, offers a synthesis of research critiquing different understandings of disability. This part of the review will provide a framework with which to assess the approaches adapted by a broad range of intervention studies (undertaken in stage two of the project). The review will explore six inter-related themes by:

- identifying and summarising the range of disability models, definitions and theories and assessing their potential contribution to public health research and policy;
- locating different definitions, models and theories within the field of disability studies and the social and political movements of disabled people;
- appraising how well different definitions capture the diverse range of experiences associated with disability, with a particular focus on how different causes, aetiologies

and trajectories mediate this experience, including a consideration of the impact of co-morbidities;

- assessing whether and how the different consequences of impairment and the context in which it is realised inform debates, including a focus on how well different theories of disability take account of broader socio-demographic variables and experience;
- investigating the consequences of adapting particular terminologies, study designs and outcome measures when evaluating public health interventions; and
- examining different approaches to public/stakeholder involvement.

4.1.1 Reviewing the literature on models and theories of disability

Scoping reviews provide a broad overview of a research field and are regarded as particularly useful when researching topics characterised by diverse approaches (Arksey and O'Malley, 2005; Davis et al., 2009; Grant and Booth, 2009; Levac et al., 2010; Booth et al., 2012). We will specifically employ Arksey and O'Malley's widely-used framework, which we have employed in an earlier scoping review and which helpfully parallels that used for more conventional systematic reviews. This framework provides a structured approach but also incorporates an iterative searching process, with search terms subject to refinement in the light of the studies identified. Our work, for example, offers a systematic review of the literature on disability in so far as we have sought to identify, appraise and summarise relevant works according to an explicit and reproducible methodology. Consequently, our account is more akin to a knowledge review. Such reviews, developed by the Social Care Institute for Excellence (http://www.scie.org.uk/), provide a thematic, explanatory exploration of the relevant literature. Knowledge reviews are especially useful in informing more reflexive policy and practice.

A review protocol will be developed outlining and explaining all major methodological decisions taken. Identified references will be entered into an Endnote data base, which will enable studies to be retrieved by either key word, subject heading or MESH term searches. Relevant studies will be identified through:

- searches of major electronic data bases;
- crosschecking with major publications in the field of disability studies, history and policy;
- scanning reference lists of relevant papers;
- internet searches;
- key books and book chapters (an important source of literature on this subject);
- major policy documents;
- consulting experts in the field by cross-checking key texts with members of the project steering committee.

All resources will be searched from 1990 onwards; the selection of the start date is based on the observation that this is where path-breaking critiques and new models begin to appear in the UK (as seen in the work of writers like Mike Oliver, Colin Barnes, Jenny Morris, Nasa Begum and Ossie Stewart). Such authors also capture the history of the various disability and civil rights movements, which go back to the 1960s, thereby adding further context and locating material within broader social movements.

Our initial search strategy will include the following electronic databases: MEDLINE, CINAHL, PsycINFO, Social Sciences Citation Index (SSCI) and SCOPUS. We will set an inclusion and exclusion date (1990-2014). We will supplement the electronic data base searches with hand searches of key journals, along with website and grey literature searches (such as the Conference Proceedings Citation Index). We will also include hand searches of relevant conference abstracts in research on models and theories of disability; and use snowballing techniques to include websites, reference list checking and Google scholar.

Our electronic searches will be supplemented and collaborated by a hand search of the major publications in the field of disability studies, history and policy. Initial work suggests these journals are likely to include: Disability & Society, Disability Studies Quarterly, Scandinavian Journal of Disability Research, Journal of Intellectual Disability Research, Journal of Disability Policy Studies, British Journal of Social Work, Social Theory & Health, Ethnicity & Health, Social Science & Medicine and Human Rights Quarterly.

In identifying MESH terms we will include experience from a range of different physical, intellectual and mental impairments, while reflecting the different political, economic and cultural disabling consequences of having a lifelong, acquired or fluctuating condition, which will be cross-referenced against those used in disability studies, sociological literature and public health policy. Potential MESH terms include ‘model*’, ‘theor*’, ‘disab*’, ‘handicap*’, ‘persons with disabl*’, mentally disabled*’, and ‘chronic disab*’. The list of MESH terms is not exhaustive and will be double-checked with our steering committee and against MESH terms used other reviews. Following testing of these terms against a sample of ten papers and advice received from the project steering committee, a final search strategy will be agreed.

We have undertaken initial pilot searches, checking if there was enough potentially relevant material. For example, randomly checking the PubMed database (from 2011-2013) using the MESH terms; ‘model*’, ‘theor*’ and ‘disabl*’, enables us to retrieve 526 papers. We randomly sampled 40 papers. After checking the abstracts in accordance with our selection criteria we were left with 3 studies. This indicates that 7.5% of studies may be useful or in other words thirty papers. This is before we have cross-checked the references or citations, which is likely to add additional relevant literature. The full period of review (1990-2013) is, therefore, likely to generate sufficient papers.

In addition to peer-reviewed papers, we will include the major books and theories on disability theory and sociological theory linked to disability (such as that on chronic and long term illness) as well as public health policy documents from national and global institutions such as the Human Rights Commission, World Health Organisation, the United Nations, UNICEF, the IMF and the World Bank. We will draw up an initial list largely based on the volume of citations. We will discuss and agree with our Steering Committee the more influential and most important texts (books and chapters) on disability theory, models and definitions.

Our inclusion criteria mean that an output (paper, report, book) will only be considered relevant if it is in English; informed by one or more of the key guiding issues highlighted in the review questions; clearly focused on models and theories; and meets our operationalisation of the study objectives/review questions. A data extraction sheet will be designed, collecting details on the six inter-related themes, outlined above. It will include identifying and summarising the range of disability models; assessing their potential contribution to public health research and policy; and appraising how well different definitions capture the diverse range of experiences associated with disability. Two members of the team will agree an inclusion of a publication and in cases of disagreement, consult with other members of the team.

4.1.2 Interpreting and analysing the literature

In interpreting the literature, we will employ an accessible framework in which to make sense of the different theories of disability, in a way consistent with public health research (White, 2011a &b). Our framework will follow a similar analytical approach to the one used by ONS in its harmonisation of disability categories (http://www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--51--autumn-2011/index.html).

This part of our review will identify and summarise the range of models and theories, including strengths and possible limitations in dealing with diverse experiences; and their potential contribution to public health research and policy.

To ensure a review sensitive to the needs of public health research, our analysis will reflect three broad themes. First, we will assess the extent to which the various models and theories can be connected to the broad concerns of public health. It will also assess the potential of adapting universal and inclusive research designs that enables the experience of those with disabilities to be captured by mainstream public health research. Second, we will explore the extent to which theories and models capture the diverse experiences associated with disability, by comparing possible differences associated with lifelong, acquired or fluctuating conditions; and the mediating impact of different types of impairment and embodied states, such as those associated with mental health and learning disability and co-morbidity. Third, we will note whether and how different models and theories incorporate diversity of experience within the disabled population, including the different experience of children, young people and adults (including older people), potential differences by age and cohort as well as by gender, socio-economic background, ethnic and cultural background and sexual orientation.

The review will explicitly focus on the questions highlighted in the commissioning brief, concerning terminology and categorisation of disability; lifecourse approaches to researching disability; PPI and stakeholder involvement in disability-focused research; and inclusive and sensitive study designs and outcomes. This will produce a framework with which to judge the design of the interventions identified in the next stage of the review.

4.2 Stage two: reviewing public health interventions

The second stage of the project will assess the extent to which the current evidence on public health interventions connects with the different theories and modes associated with understanding disability. By taking the Cochrane (international) Database of Intervention Reviews as our sampling frame, we will purposively select 30 reviews with a public health focus (i.e. non-healthcare interventions) in which people with disabilities are identified as a key target group, to enable us explore the potential of inclusive designs. The sample will be selected to ensure our reviews includes different types of interventions and a broad range of standardised measures; a range of disabilities, such as mental health, learning disability, hearing impairment, physical impairments and long standing chronic conditions, while including co-morbidities; people at different stages of the life course; studies focusing on diverse ethnic and cultural backgrounds; and that take into account the possible impact of broader inequalities. A combined MESH term of ‘disability’ and ‘intervention’ generates 643 results. On checking a sample of 30 reviews, each - on average - included 16 studies (with a range of 3 to 51). This would give us material on 480 studies.

We will then purposively select a further 30 generic reviews, to cover broader public health interventions, which could potentially benefit those with disabilities, so as to gain insights into the ability of mainstream research to capture the experience of disability. We will look to include a range of public health interventions an a broad use of standardised measures; people at different stages of the life course, a range of ethnic and cultural backgrounds and take into account the possible impact of broader inequalities. An initial review suggests there are at least 700 potential reviews. After checking a sample of ten reviews, each cited on average 12 studies (with a range of 3 to 64), which would give us material on 360 studies.

To ensure we can capture a diverse experience of disability, we will supplement our search strategy by purposively sampling databases held by the Campbell Collaboration and Joanna Briggs Institute. This will add further nuance to our analysis and enable us to explore particularly interesting and underdeveloped issues, which emerge from our use of Cochrane reviews. Further, we will be able to follow especially relevant studies which have yet to report, but could contain pertinent information missing from the published reviews. This is an important consideration in what is a rapidly moving area.

This stage of the review process will build on the first review by:

- mapping and offering a critical commentary on the models and theories of disability underpinning (implicit or explicit) evaluations of public health interventions;
- considering the terminology and categorisation of disability used;
- assessing whether a lifecourse perspective is evident;
- exploring the use and relevance of outcome and effectiveness measures to the experience of those with a disability;
- evaluating the extent to which research designs include participants with different types of impairments and disabilities, from different socio-demographic groups; and
- examining methods of participant, public and stakeholder involvement,

A purposive sample of reviews (given the range and volume of studies likely to be included in each review) should provide sufficient evidence to assess how far the current design of intervention studies takes account of the diverse experience of disability. Our approach will also enabling potential shortfalls and gaps to be identified.

More detailed analysis of a selection of key papers, included in the reviews and selected purposively, will further ensure our work can accommodate a broad coverage. Working with the Cochrane Database will ensure the included studies have met relevant quality criteria to merit inclusion.

4.2.1 Approaching the literature

In identifying Cochrane reviews - and supplementary databases held by the Campbell Collaboration and Joanne Briggs Institute - in which people with disabilities are identified as a key target group, we will adapt a broad definition of disability and public health intervention with MESH terms reflecting: disability/ies, illness, impairment(s), long term conditions, mental health, learning disabilities, intellectual and cognitive impairment, persons with disabilities, handicap interventions, effectiveness, measurements and outcome tools (including economic evaluation). In further refining MESH terms, we will use insights gained in the first stage of the project. Generic reviews covering broader public health interventions, which could potentially benefit those with disabilities, will similarly adapt a broad definition of public health intervention, so as to reflect the current state of commissioned research in all its complexities.

Inclusion criteria include reviews published between 2000 and 2014; involving any form of impairment; involving both adults and/or children; and any public health intervention linked to a public health outcome. Prior to 2000, constituent studies are less likely to be 'disability' sensitive. Preliminary analysis of the data base, using the above inclusion criteria and the following MESH terms, suggests there are sufficient reviews (as demonstrated above). Appendix B provides a flow chart summarising a) scoping of reviews including people with disabilities and b) scoping of generic review.

As with the first review, a protocol will be developed outlining all major methodological decisions taken. Identified references will be entered into an Endnote data base, which will enable studies to be retrieved by either key word, subject heading or MESH term searches.

4.2.2 Interpreting and analysing the literature

Stage two of the review will specifically assess the potential for universal study designs, ethical conduct (including consent procedures) and inclusive execution of public health research. In exploring reviews of interventions targeted on those defined as having a disability, we will have collected insights about the extent to which different forms of disabilities can be accommodated in research designs as well as the various strategies used to achieve such inclusion. Examining more generic reviews of public health interventions will enable us explore the extent to which disability is accommodated in more mainstream research. Taken together, these different sorts of reviews will enable us to identify the possibilities for a more all-encompassing approach, which can accommodate a diverse range of experiences and thereby maximise the generalizability of findings in a way consistent with how current interventions studies are undertake. Key questions include:

- was an inclusive approach considered and used to inform the design and conduct of studies?
- did study design privilege the inclusion of some impairment types and disability groups over others and if so, what types of disabilities are more likely to be accommodated?
- what possible accommodations could be identified to make for a more inclusive research design?
- were accommodations - potential or otherwise – identified by authors as jeopardising the scientific integrity of the research evidence?
- were communication difficulties used to justify the exclusion of certain people and to what extent could these be regarded as legitimate?

- how were those with disabilities treated when recruiting to the study?
- how did the findings discuss disability?
- did the authors consider the extent to which their findings could be generalised to include the experience of those with disabilities?
- to what extent could the findings produce relevant and universal evidence? and
- to what extent could study designs be perceived to be disablist or ableist?

To help answer these questions, the content of reviews will be appraised by using the Effective Public Health Practice Project Quality Assessment Tool recommended by the Cochrane Public Health Review Group. This includes: an examination of sampling strategy, response and follow-up rates, intervention integrity, statistical analyses and assessment of adjustment for confounders. We will use quality appraisal criteria for descriptive purposes and to highlight variations between reviews (and studies). We will also be using the Cochrane-Campbell Equity Checklist for Systematic Reviews (or PRISMA-Plus) to evaluate the extent to which studies included in reviews engaged with equity, thereby providing evidence for good research practice, which has successfully engaged with the diverse experience of disability.

The initial screening of identified reviews will be conducted by two reviewers. Any discrepancies will be resolved through discussion and, if consensus is not reached, with the project team. A data extraction sheet will be designed, collecting details on the intervention being evaluated; study designs; target populations; inclusion and exclusion criteria; measures used and their appropriateness to understanding different types of disability; user and public involvement; and relevance of findings to a broad and diverse experience of disability. We will note where reviews include studies with participants from poorer backgrounds, ethnic minority populations and other marginalised groups. We will also comment on the extent to which studies – specific or generic – accommodate the different circumstances in which disability is negotiated and experienced.

To refine and sensitise our findings, for half of the reviews selected we will identify one key paper and interrogate it in more detail in accordance with the key questions identified above. This will provide us with a sample of purposively selected 30 papers. Reviews targeted on disabled people, will be selected to ensure they reflect the diversity and range of disabling experiences. When sampling we will be especially sensitive to include common and less common forms of disability; different trajectories and causes of impairment; and reflecting differences associated with gender, socio-economic position, ethnicity, sexual orientation and lifecourse. If insufficient diversity is not achieved, supplementary material will be collected from reviewing material in databases held by the Campbell Collaboration and Joanne Briggs Institute. Material from these papers will supplement the insights gained in our review of reviews, thereby allowing us to cite more detailed observations in support of our main arguments. Such examples will be invaluable when drawing out recommendations to commissioners. Given that we are also looking for examples of appropriate stakeholder engagement and involvement, which tend not to be detailed in publications, we will also contact authors of these papers and ask for supplementary material.

4.3 Synthesising the two reviews

Our account, synthesising information from a variety of sources, will employ a narrative, thematic and interpretative approach. Synthesis of the two reviews will link different models and theories of disability to an understanding of public health research. The synthesis will demonstrate the breadth and depth of the literature on disability, including possible tensions when applied to public health research. This will be connected to an assessment of research design and inclusive research strategies. By integrating the findings of the two reviews, we will be in a position to provide best practice guidelines on: terminology and categorisation; deployment of lifecourse perspectives, participant; public and stakeholder involvement; and the appropriateness of study designs and outcome measures in exploring the diverse range of experiences associated with different disabilities. By evaluating a range of strategies, our findings will inform the commissioning of both future research on targeted public health interventions and generic interventions designed to mainstream disabled people/groups. In addition to identifying best practice on how to do research with a broad range of disabled people, we will also consider the extent to which research findings can be universally adapted.

4.4 Refining and presenting the findings

Once the synthesis is complete, the research team will draft a research briefing, summarising our findings and providing recommendations for commissioners of public health research. Before we finalise the briefing, it will be introduced at four regional deliberating panels involving politically active disabled people. We will hold a further panel, aimed at commissioners and researchers. Comments from all five panels will be used to refine the guidelines. This will ensure the briefing has some grounding in the expectations and experiences of different stakeholders.

The final briefing will briefly present the current state of play, but more importantly assess the different options available to commissioners by offering advice and recommendations on how best to include and capture the diverse range of experiences associated with disability, in evaluations of public health interventions. It will illustrate examples of good practice and provide an assessment of different strategies through which to promote a more inclusive research agenda. The briefing will also comment on the extent to which current methods of intervention research can be universally adapted to ‘mainstream’ the experience of those with disabilities.

In achieving this, the briefing will include a critical discussion about the value of adapting a more socially-orientated model of disability, in a way consistent with the needs of public health research. Recommendations will debate the tensions raised by commissioning more inclusive public health research, able to include the diverse range of experiences associated with disability. This will then be connected to assess the practicalities of defining appropriate research questions that adapt inclusive sampling strategies, use relevant outcome measures and establishing appropriate user involvement and preference. To this extent, the final recommendations and briefing will balance sensitivity to more social and emancipatory models of doing research, while recognising the practical demands of producing evidence-based public health research.

To further disseminate our work to a broad range of stakeholders an accessible, a shorter summary of our work will be made available in a variety of different formats.

4. STUDY POPULATION

As this is a scoping review examining the disability studies literature and literature concerning public health interventions linked to disability, the study does not have a setting *per se*. It will, however, engage with international literature and include studies, from a diverse range of methodological backgrounds and from primary care, community or social settings. We will note the different settings of studies and the impact these might have on the findings. It will also engage with a diverse range of disabilities and social experiences.

5. SOCIO-ECONOMIC POSITION AND INEQUALITIES

The purpose of the research is to promote the inclusion of disabled people in research on public health interventions in ways that are relevant to their experiences; take account of the diverse consequences and circumstances of impairments; and are sensitive to the position of different socio-demographic and cultural groups. Such research will inform future public health research, enabling it to take better account of the complexities associated with individual, social and political dimensions of disability and impairment. In so doing, the project will help to address social exclusion and social inequalities for disabled people. Its findings, therefore, will have a wide audience and contribute to current understanding of disability and public health in a way that addresses previous neglect (as recognised by the commission brief).

6. OUTCOME MEASURES

This is not primary research but a scoping review. To this extent we will examine what kinds of outcome measures are used in public health research on disability and gauge their appropriateness, as viewed from a variety of different perspectives. In terms of the review, we offer a synthesis of literature to understand how different models and theories could inform research into the effectiveness of public health interventions, in a way that informs future public health research strategies and captures the complex and diverse nature of disability (and impairment) as experienced by different demographic groups.

7. ETHICAL ARRANGEMENTS

This is a scoping review and not primary research. The research, however, will be presented to the respective (York and Lancaster) University Ethics Committee of team members for formal approval. It will also be presented to the Department Working Group on Patient and User Involvement and advice sought on the project's approach to user engagement. We will also follow INVOLVE guidelines, when engaging with participants and stakeholders (http://www.invo.org.uk/#).

8. RESEARCH GOVERNANCE

The research will be formally managed in accordance with the University of York's and Lancaster's ethical, financial, health and safety and quality guidelines. The nominated sponsor of the research is the University of York.

The study will also have a Study Steering Committee, with an independent chair. This will formally monitor progress of the study in accordance with key milestones and will be made up of academics, commissioners, practitioners, third sector organisations and people with disabilities.

9. PROJECT TIMETABLE AND MILESTONES

Months 1 to 4:	Begin first stage of scoping review; establish networks to support research; hold first advisory meeting; offer research workshop to introduce research;
Month 5 to 6:	Write up first part of scoping review and establish theoretical framework to apply to stage two; prepare paper for publication;
Months 7 to11:	Begin, complete and write up second stage of scoping review; hold second advisory group meeting;
Months 12 to 15:	Synthesise findings from two reviews and prepare final write up; prepare publications, draft guidelines and accessible summary;
Months 16 to 18:	Present findings five deliberating panels; refine findings and finalise report, guidelines and summary; reproduce guidelines and summary; hold third advisory group meeting; disseminate findings using existing networks.

10. EXPERTISE

The work will require theoretical and empirical engagement, which utilises the extensive experience and skills of different members of the team. The research brings together an established team with considerable experience of disability and inequality, along with extensive networks, which will be used to disseminate the findings. Their ability to connect different models of disability with broader debates about public health is a particular strength of the team. The team are aware of the need for sensitivity to more social and emancipatory models of doing research, while recognising the practical demands of producing evidence-based public health research.

Professor Karl Atkin (University of York) is a sociologist with an interest in disability and a background in doing qualitative research in multi-disciplinary and culturally diverse settings. His work has a particular focus on understanding the social consequences of various long standing, disabling conditions. He will lead the project.

Professor Hilary Graham (University of York) has a background in sociology and social policy. She has a track-record of research on public health and social inequalities, including studies related to intellectual disability (with Eric Emerson and Chris Hatton at Lancaster University). She was Director of the ESRC Health Variations Programme (1996-2001), which funded research on the links between social and health inequalities, and also Director of the Public Health Research Consortium (2005-11), which focused on interventions to improve health and tackle health inequalities. She is a member of a range of research and policy committees, including the NHS Outcome Framework Technical Advisory Group (OFTAG), and will advise on public health and inequalities.

Professor Carol Thomas is a sociologist who has published widely on disability studies and this will form the basis of her advice to the project. Currently, she has research interests in two main areas: (i) the sociology of disability in Disability Studies (ii) the sociology of cancer experiences and end of life care. She has also written widely on chronic illness, women’s health, care and end of life service provision. She is also on the editorial board of several influential journals in the field of disability studies and sociology theory.

Professor Chris Hatton has a background in psychology and is co-director of the Learning Disabilities Public Health Observatory operated by Public Health England. He has published widely on the social and health inequalities experienced by people with learning disabilities and on policy innovations designed to improve the health and wellbeing of this group.

Dr Maria Berghs (Research Fellow, University of York) is a social and cultural anthropologist interested in improving health care services and access for disabled people through inclusive research practices. She is familiar with UK and global public health policy debates related to disability studies. Her former research examined the relationship between disability and poverty which means she is familiar with different types of measurement tools for disability and their strengths and limitations in differing contexts.

11. DISSEMINATION AND IMPACT

By generating insights into how models and theories of disability can be used to research the effectiveness of public health interventions, the project will have a strong anticipated impact. Our findings will be of interest to a wide variety of stakeholders, including: public health research commissioners; public health researchers; (potential) service users; third sector stakeholders. The team is well placed to ensure strong dissemination and impact. Each member of the team has relevant specialisms linked to disability, public health and/or health inequalities research, along with established networks. Dissemination will be tailored to different audiences.

Academic dissemination will be via submission of papers to high quality peer-reviewed journals in the fields of public health, sociology, and disability studies. These articles, applied in nature, will illustrate how theory, public health policy and inclusive research design and practice can be integrated. Conferences in the field of public health, medical sociology and disability would also be targeted.

This will be supplemented by a research briefing – the key outcome of the research - offering guidance and aimed at research commissioners, but with a more general relevance for policy makers, researchers, public health practitioners as well as the general public. The briefing will emphasise key points of relevance and assess the implications and consequences of different strategies when commissioning research. It will be especially concerned to illustrate examples of good practice, while providing an assessment of different strategies, on which to base a more inclusive research agenda (as indicated in section 4.4). A draft research briefing will be introduced at four regional deliberating panels involving politically active disabled people. We will hold a further panel, aimed at commissioners and researchers. Comments from all five panels will be used to refine the guidelines.

The research briefing will be distributed widely with help of the project advisory group, deliberating panels and contacts built over the course of the research, through email lists and relevant third sector websites. Possible third sector websites and visited stakeholders include umbrella organisations such as the Disabled People’s Council, disabled people’s organisations such as Scope and organisations that give advice and support to disabled people such as the Equality and Human Rights Commission.

To promote accessibility to outputs from the project, we will also ensure that the research briefing is made available in a variety of media (including social media) for disabled people and their organisations. This includes audio and braille copies of the research briefing as well as large print versions. A two page accessible summary will also be made available to user stakeholders.

Our research may also be of interest to policy makers and advisory committees such as the National Institute for Health and Clinical Excellence, Public Health England, Public Health Interventions Advisory Committee and we will include them in our dissemination activities.