

Effective public involvement in the HoST-D Programme for dementia home care support: from proposal and design to methods of data collection

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Abstract

Public involvement is an important element in health and social care research. However, it is little evaluated in research. This paper discusses the utility and impact of public involvement of carers and people with dementia in a five-year programme on effective home support in dementia, from proposal and design to methods of data collection, and provides a useful guide for future research on how to effectively involve the public. The Home Support in Dementia (HoST-D) Programme comprises two elements of public involvement, a small reference group and a virtual lay advisory group. Involving carers and people with dementia is based on the six key values of involvement - respect, support, transparency, responsiveness, fairness of opportunity, and accountability. Carers and people with dementia gave opinions on study information, methods of data collection, an economic model, case vignettes and a memory aid booklet, which were all taken into account. Public involvement has provided benefits to the programme whilst being considerate of the time constraints and geographical locations of members.

Keywords: dementia; service users; carers; patient and public involvement; home support; intervention

Introduction

Patient and public involvement in health and social care research is an important element that can benefit research questions and studies in a myriad of ways. It allows for the needs, wishes, and experiences of the public to be taken into account, to clearly integrate those at whom the research is directed. The impact of public involvement has been little explored however, although a recent investigation of a mixed group of researchers, public members, commissioners and health professionals has endorsed the feasibility and value of assessing its impact (Barber et al., 2012).

Public involvement can take several approaches. In a recent study to develop an intervention for home care support in dementia, Burnell and colleagues (2015) conducted a modified Delphi process and an anonymous reading consultation with service users. These elements of public involvement helped shape the role of peer supporters in the final intervention, as well as making changes to the study documents. A centrally organised patient, public, and carer involvement body can also provide several benefits to individual and separate studies. The formerly known as Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) for example has shown to offer an effective public involvement service, by helping studies in the recruitment, development of patient information sheets, and setting up a patient reference panel (Iliffe et al., 2013). All these benefits have been corroborated in a recent systematic review, ranging from impacts on the development of user-led research objectives to more effective study recruitment (Brett et al., 2014).

A useful typology for user and researcher roles for involvement in action research was promoted by Tripp (1998) that range from consenting, consulting, co-operation, collaboration to collective action along a continuum of researcher in control, shared control to users in control. More recently the National Institute for Health Research has outlined the key values of public involvement in research in its values and principles framework (INVOLVE, 2015). These six values include respect (recognition of the contributions of public members and the respect for their knowledge and experiences); support (flexibility in their involvement and reimbursement of expenses); transparency (open discussions about the expectations of the public members' involvement in research); responsiveness (collaborative decision-making and commitment by researchers to act upon the input provided by public members); fairness of opportunity (public involvement opportunities are easily accessible and information provided is easily comprehensible); and accountability (researchers are accountable to researchers and vice versa).

This paper discusses the patient and public involvement element of the HoST-D (Home Support in Dementia) Programme. The HoST-D programme has been running since 2013, and involves a total of nine individual projects which are outlined in Figure 1, and range from evidence synthesis (Project 1.1) to an observational study of models of home support (Project 2.2), a trial of memory aids (Project 2.1), to a discrete choice experiment on preferences in home care (Project 3.2) and costing analyses (Projects 1.3, 3.1, and 3.3). The ultimate goal of this programme is to develop a dementia toolkit, synthesising the evidence for home support and providing guidance to managers and commissioners in the NHS and partner agencies. This will be tested by commissioners and service managers being asked to use the toolkit within normal working practices within the commissioning and contracting cycle.

The aim of this paper is to disseminate the lessons we have learnt so far from setting up two patient and public involvement groups with people with dementia and their carers, one small face-to-face reference group and one virtual lay reference group, and to disseminate the methods used and benefits in shaping the research design of the programme, methods of data collection, intervention and economic modelling analysis. Patient and public involvement research has highlighted the need for more research into care for people with dementia and their carers (Kelly et al., 2015), indicating how it can offer suggestions for relevant lines of meaningful research enquiry for those most likely to benefit.

[insert here Figure 1]

Methods

The Groups

The HoST-D programme involves two patient and public involvement groups: one small reference group and one virtual lay advisory group. The small reference group, drawn from within the North West of England, meets biannually face-to-face, and comprises between eight to 12 informal carers (current and previous), people with dementia and lay public involvement experience in research programmes and members of the research programme (range 11 to 15 per meeting in total). Service users, people with dementia and carers were recruited with the assistance of former DeNDRoN from groups meeting at The Brain Charity (formerly Neurosupport) in Liverpool. The virtual lay advisory group is an email-based public involvement, which comprises 20 informal carers who were recruited via the [Uniting Carers database, a national network of current and former family carers of people with dementia](#), across England and were a convenience sample of self-nominating to participate in this aspect of the programme. The group is consulted when needed.

Types of involvement

Carers and people with dementia have a consulting, and collaborating, role in the HoST-D Programme and have a shared control approach with research team members (Tripp 1998), responsible for patient and public involvement. [Referring to the INVOLVE values and principles framework of public involvement in research \(INVOLVE, 2015\), developed by the National Institute for Health Research](#), the HoST-D public involvement element incorporates several of the six key values outlined. The first value integrated throughout is *respect*. Public members (carers and people with dementia) are included as key partners in research, which is for example demonstrated by one of the members being a co-investigator on the grant proposal, two members named in the proposal as lay patient and public involvement representation and having a role on the Programme Steering and

Management Committees, also by members of the reference group being co-authors of this paper. Members of the reference group have been involved from the outset, in order to shape the research proposal and protocol before funding was awarded. Furthermore, the contribution of all members of the reference and lay reference group are recognised by acknowledgement in outputs arising from the Programme on projects they have contributed.

The second value is *support*. Our group offers flexibility in involvement, in that the date is always organised based on the participants' availability, and if participants are unable to attend a meeting, they can join again the following one. Furthermore, the HoST-D programme is supportive in that it covers participants' travel expenses and shopping vouchers for their participation after each meeting.

The third value is *transparency*. The HoST-D programme offers transparency in several forms. We "openly discuss the purpose, scope, and expectations" (INVOLVE, 2015, p.8) of participants about their involvement in the research. In particular, we discuss the topics of each session both in advance and at the beginning of the meeting, and outline the ways in which their input has helped inform the programme to date based on previous meetings and will help in shaping different elements and projects of the programme. From the point of view of the participants, they can be open about their abilities and the extent to which they can contribute. One person has reading and speech difficulties for example, so this is taken into account during the meetings and when distributing any information, such as meeting notes. These meeting notes are provided in audio format to allow the inclusion of everyone.

The fourth value is *responsiveness*. The Project Management Steering committee has two patient and public involvement representatives, and one of these representatives also serves on the Data Management Committee. The research team is actively shaping research design and written documents such as information sheets or vignettes, intervention content, methods of data collection and economic modelling analysis as part of a project based on the input received from members of the small reference group and the lay reference group.

The fifth value is *fairness of opportunity*. When recruiting public members to take part in the public involvement element of the HoST-D programme, it was ensured that this opportunity was accessible to anyone who was a carer or a person with dementia. Only those who speak English were recruited for the public involvement. All information provided to members is presented in easily accessible formats and written in plain English with large font. One example is discussing the components of effective home support, thereby introducing a real-life comparison such as baking a cake with the correct ingredients. Moreover, all material is provided in alternative format where required. In particular, meeting notes and similar are being audio-recorded for members with reading difficulties.

The sixth value is *accountability*. The research team is accountable to carers and people with dementia involved in the reference groups by openly discussing how their contributions have been integrated into the research design and methodology. This is always conducted at the beginning of each small reference group session, and the lay advisory group is informed about the changes as a result of their input by each subsequent email involvement. The impact of the members' involvement

is also outlined in every output arising from the programme, such as the protocol for the evidence synthesis (Clarkson et al., 2016). The research team also seeks evaluation and feedback at the end of each small reference group session with the possibility of improving subsequent sessions (most useful and least useful aspects of session and how could be improved), if required. At the beginning of the HoST-D programme, members of the group had their roles and responsibilities outlined in powerpoint slides, group discussion, and handouts and were agreed. These responsibilities included to meet twice a year, if possible; advise on aspects of the proposed methods; comment on project information sheets and methods of data collection; advise on the research team's interpretation of findings and their implications for people with dementia and their carers; advise on the best methods of dissemination; and respect people's points of view and that information about the project and members' views are confidential. Researchers and members of the public involvement groups jointly assess the impact of their involvement throughout the programme, and will reflect on this particularly in the last session.

Process of involvement

The small reference group has so far met six times. All meetings were based on individual elements of the programme (see Figure 1), whilst the first meeting took place before funding for the programme was secured in order to strengthen the funding application. During each meeting, participants were provided with free lunch, shopping vouchers, and reimbursement of travel expenses, in acknowledgment of their participation, commitment and time involved. As Figure 2 outlines, the process of involvement is cyclic, in that first the research design for a specific study on the HoST-D programme is specified and elements for discussion with patient and public involvement members are selected. This is followed up by the PPCI meeting, in which members are first informed about how their previous contributions have made an impact, and subsequently by receiving their input on the elements selected in the first step. Once the meeting has been held, meeting notes are written up and distributed, whilst the feedback from members is integrated into the research design, followed by the ethics submission. This cyclic process is then repeated.

In the first meeting, participants gave feedback on the proposal, protocol and research design of the suggested programme. In particular, the idea of various forms of support to both people with dementia and carers, central to the programme, was seen as a good one. This feedback was used in amending the research proposal and in particular was used in responding to reviewers' comments on the proposal, as submitted to the funder.

In the second meeting, the first meeting of the programme, we focused on effective methods and services in dementia home support, and enquired about components of effective home support. This discussion was linked to Project 1.1, the evidence synthesis on effective home support in dementia.

In the third meeting, participants discussed carer support services and elements that were helpful and less helpful. This discussion fed into Project 3.2, which explores preferences of home care services by informal carers. For this purpose, participants were suggested to imagine home support

like baking a cake, and that finding the correct ingredients to bake a cake (the equivalent to selecting the most effective components of home support), results in a good cake (the equivalent to an effective home support service, which may improve quality of life, everyday functioning, or carer stress, for example). In addition, members were consulted about the acronym of the overall programme grant.

In the fourth meeting, participants contributed to the economic model of the programme (Project 1.3), which aims to cost home support services for dementia. Participants were provided with a preliminary model for home support in dementia, depicting the various pathways from the diagnosis to the final stage of the condition.

In the fifth meeting, carers and people with dementia provided feedback on a memory aids manual for Project 2.1, the trial of the programme which examines the effects of memory aids on everyday functioning and well-being (the DESCANT trial – Dementia Early Stage: Cognitive Aids – New Trial).

In the sixth meeting, carers and people with dementia discussed their experiences of memory clinic and hospital visits, as well as the length of time from first noticing problems to a diagnosis and long-term care admission. Input from participants fed again into Project 1.3, thereby furthering the development of the economic model. Whilst participants were provided with a first draft of a model with many components in the fourth meeting, participants received a more polished version of what the economic model may look like focusing on four major life events including diagnosis, memory clinic visits, hospital admission, and nursing home admission.

The virtual lay reference group has been consulted via email twice so far. The first consultation took place in the first year of the programme, and focused on Project 3.2, a discrete choice experiment (DCE) on carer preferences of home care services in the later-stages of dementia. Carers were asked to give their feedback on whether the information sheet and consent form of the project were easily understandable to a lay audience. Moreover, carers were asked to comment on the actual DCE questionnaire for later-stage dementia. The second consultation took place one year later, where carers were consulted about Project 3.1. This project examines the costs of care from the perspectives of informal carers and staff. For this purpose, carers and staff are provided with five case types of real people with dementia, based on the UK dataset of a previously conducted European programme into transition in long-term care in dementia (Verbeek et al., 2012), and allocate a variety of home care services to each case type. These will then be compared across carers and staff. The consultation of the lay reference group involved those 20 carers to feedback on the language of the five case types and whether these were easily understandable.

[insert here Figure 2]

Impact of public involvement

Reference group meetings

Meeting 1 (Proposal development stage Autumn 2011)

The initial meeting at the draft proposal stage included asking the group on their views of home support for people with dementia and carers, what is available, what should be available and would it make a difference, does home support change over time and if so what is needed and when? How can we improve support for people with dementia and for carers, does the research proposed make sense and is there anything missed? The session was followed by evaluation and feedback in the same format for each subsequent session.

The group described current home support offered by health, social services and the voluntary sector and its variability across locations. Views on home support that should be available were GP home visits, respite care, practical help and care coordination by a professional. They recognised that home support and care needs changed over time and differed according to individual needs. Improvements for people with dementia and their carers included training of professionals and carers, appreciation that home support was preferable to care home placement, support for carers, improvement in care co-ordination, communication, information and sign posting to it, support for other family members, continuity of care and avoiding closing care down as difficult to reinstate and practical help for carers. The group agreed the proposed research made sense and noted an omission for comparing the views of professionals, carers and those with early stage dementia, subsequently included.

Meeting 2 (Programme commenced September 2013- Autumn 2013)

The second meeting focused on the components of effective home support, and produced helpful comments showing that no one model of home support is helpful to any person with dementia. PPCI members shared their personal experiences of effective home support, ranging from befriending services offering a personal aspect to support, to day care centres:

“A friend’s mum also has dementia, and the only way to get her clean is for day centre staff to say ‘Everyone is getting a shower today’.”

Dyad

Regarding the individual 13 components of home support that were suggested, participants stated that it is necessary to know the stage of dementia in order to consider the most suitable component. Additionally, participants highlighted that on some days, people with dementia were able to complete specific tasks, but that on other days, people with dementia were unable to due to behavioural problems. Participants also gave specific examples for each component, such as the component of ‘behaviour management’ for carers should include music to stimulate and relax.

These comments were successfully integrated into the evidence synthesis, in terms of the range of components (e.g. education and health promotion for carers, help with daily living activities for people with dementia) that may be necessary in effective home support. These components were also used in the project investigating people with dementia and carers’ preferences for care (the ‘Discrete Choice Experiment’). The input from carers and patients during this specific meeting is acknowledged in the first output from the programme (Clarkson et al., 2016).

Meeting 3 (Spring 2014)

The group's discussions were able to contribute to the framing of the evidence synthesis in terms of the 'mechanisms' by which different components may act upon different areas of life of those supported. For example, considering a 'carer support service', the component of 'emotional/peer support' may act to enable the carer to be more confident and allow them to 'open up':

"A group of carers, once a month for two hours, sharing what happened last month, helps with problem solving. There is a guest speaker, information sharing, and there is no professional there."

Female carer to husband and father-in-law

On the other hand, the component of 'health advice/promotion' may enable the carer to 'feel more robust'. Both these mechanisms may lead eventually to the carer feeling more competent and less guilty about decisions, such as placing a relative in a nursing home:

"Admiral Nurse prepared me [information/ support] for placing my dad into residential care. She helped to plan end of life for my dad. I was forewarned about the future."

Female carer about her father

Meeting 4 (Autumn 2014)

The focus of this meeting was to develop thoughts about an initial economic model for dementia care and in such aspects as carers' decisions about where and what services are available, their experience and opinions of home support services past and current and their choices, as to care at the different stages of dementia, early, moderate, later in the pathway.

Patient and public involvement members suggested that there are no clear pathways from one to the next element in dementia care:

"From going to the GP (with a problem) and the GP not knowing; we were referred to both the Neurological unit and to Ear, Nose and Throat, so down two pathways. In Ear, Nose and Throat we just received an assessment briefly, but the Neurological Unit took so long. We have been waiting for ever since we received the letter with a diagnosis in June finally. But since then, nothing has happened. No one at the memory clinic has helped us, and we only received a call from our GP whether he could help after our friend from the Alzheimer's Society, a chance meeting, enquired with him."

Female carer about her husband

These discussions fed into initially devising a model using specialist software, so that it reflected reality, as seen from the point of view of major actors in the process; that is, carers of those with dementia. Changes applied to the model became clear to the reference group in the sixth meeting.

Meeting 5 (Spring 2015)

From this meeting, amendments were made to the materials to be used in **the trial** – a pragmatic trial of memory aids and support in early-stage dementia. Patient and public involvement members generally suggested having a paced/staged delivery for information e.g. for each week, and over time to go through the proposed booklet. Having a contents table was considered important, and there was currently too much text on each page with graphics not always matching the text. With dementia also becoming a younger person's disease, the trial should be an early and preventive intervention.

The wording and content of particularly the memory aids manual and the Intervention Manual itself (used in the training of the main member of staff – a Dementia Support Practitioner (DSP) employed in the trial) were amended for readability and to enhance understanding.

Meeting 6 (Autumn 2015)

Patient and public involvement members provided several insights into different elements surrounding dementia care – from diagnosis and memory clinic to hospital and care home admission. Overall, the group shared mixed experiences in all areas. One carer raised the issue of lack of awareness of dementia symptoms, which can hinder receiving a diagnosis in the first place:

“There is a lot of general awareness is about memory and it should be a focus on other problems, such as falls, perceptual problems.”

Female carer

The experiences surrounding care home admissions varied also, although the group was in general agreement that family carers often feel guilty if they help their relative with dementia to move into a care home:

“A problem is when the person with dementia is not happy in the care home and when people visit they plead take me home. They may be coerced into colluding with health professionals to keep them there. It is very difficult for the family when the family feel they are being coerced and they perceive they are betraying the person with dementia.”

Male carer about his mother

The deliberations from this meeting were taken forward into revising the ‘patient pathways’, particularly for later-stage dementia, in building the economic model. Issues were clarified, such as the likely flow of people with dementia through various service configurations, such as ‘assessment at a memory service’, ‘receipt of home care’, ‘hospital admissions’ and ‘nursing home admissions’. The group were also able to give a likely range, from their own personal experiences, of particular inputs that went into building the economic model, such as number of hospital admissions over a year.

Virtual lay reference group input

First input (Spring 2014)

Carers commented on the components used in construction of the DCE and also in the ease of completion of the schedule as well as the Participant Information Sheet to potential participants. There was a divergence of views as some carers thought the schedule too long (18 questions with a mix of components that were varied in terms of their intensity) whereas some felt that it was understandable and could be completed fairly easily. From the group's comments, the Participant Information Sheet was amended to make the process of completion clearer by signalling how many questions participants were likely to expect and exactly what they must do to answer each of them (i.e. by placing a 'tick' at the end of each questions to say which service (from a choice of 'A' and 'B') they preferred.

Second input (Spring 2015)

Carers stated that the five case vignettes describing people with dementia were easily understandable, and that they could easily depict a person with dementia based on the vignettes. Hence, no changes were made, although their feedback was important to ensure that actual participants would easily comprehend the study information. The input of members of the virtual lay reference group is acknowledged and discussed in the output of this particular study (Study 3.1) (Giebel et al., 2016).

Discussion

Involving patients and carers is an important and beneficial element in health and social care research, to ensure that the needs and experiences of those are taken account of (Ashcroft et al., 2016). Public involvement not only helps in the shaping of major research proposals to secure funding, but also in the research design of smaller studies or systematic reviews (Backhouse et al., 2016; Mockford et al., 2016; Ross et al., 2005). In this paper, we have reflected upon our public involvement experiences within the HoST-D Programme, and how all six values of the INVOLVE (2015) guideline for public involvement have been integrated. The carers and people with dementia also have a consulting, and collaborating, role in the programme and a shared control approach with research team members (Tripp, 1998).

Both groups of public involvement have provided a mechanism for carers and people with dementia to meaningfully contribute to the HoST-D programme in multiple ways. There are advantages to both groups. The small reference group benefits from peer support (Drentea et al., 2006), and its form has been employed in several other studies (Illiffe et al., 2013; 2015; Thomas et al., 2015). In contrast, the virtual lay advisory group allows access for anyone regardless of location and is less time consuming. Virtual lay advisory groups have been used in other studies in health research for the same reasons, such as in the MUSTARDD-PD study which evaluates the benefits of donepezil in early dementia linked with Parkinson's disease (Illiffe et al., 2013). Moreover, the authors

described how virtual patient and public involvement accommodates for potential mobility issues of some lay members. Hence, commenting via email on patient information sheets was considered a feasible option. Other possibilities of involving service users and carers is via postal consultations (Burnell et al., 2015), online expert panels (Khodyakov et al., 2016), or via a virtual steering committee, which oversees an entire programme. Ashby et al. (2007) employed such a steering committee on a six-weekly basis, whilst sending out related documents prior to the virtual meeting. Involving older adults in such a format to discuss research with academics allowed them to grow in confidence. Although the HoST-D programme did not use a virtual steering committee, two members of the patient and public involvement group were also members of the steering committee, thereby showing good practice in involving carers with direct experience.

There were several elements of good practice implemented in both the small reference and the virtual lay advisory group, meeting the guidelines of INVOLVE. Notes were collated by two researchers (BR, CG) after each meeting to create final meetings notes for all participants, as well as for the write up of how the patient and public involvement input has guided the Programme. These notes were written in large font to aid readability, and were sent out to members of the group via email or post. One member of the small reference group had difficulties reading and speaking, so that notes were also audio-recorded. This was part of the continuous feedback that was applied at the end of each session, which allows for continuous evaluation and possible improvement to the way the public engagement element of the HoST-D Programme is conducted. As mentioned during the third session of the small reference group, print outs of all documents were considered important, so as to avoid printing costs for participants. Moreover, all patient and public involvement members from both groups were either emailed (virtual lay reference group) or handed out paper copies (small reference group) of any outputs arising from the programme, including annual newsletters and published journal articles acknowledging their involvement (i.e. Clarkson et al., 2016).

The public involvement element of the HOST-D programme further benefitted by being informed from approaches developed in a previous NIHR programme recommended for their high standard, and by including co-investigators and lay members involved in those. The *Identifying Continence Options after Stroke* (ICONS) (Thomas et al., 2015) programme involved regular face-to-face meetings with up to 12 lay members. Due to some members having aphasia, the ICONS study engaged two separate small reference groups to account for the individual needs of different patient groups. However, these groups were kept continuously the same throughout the five years of the programme, with members commenting on each aspect of the programme. In contrast, the EVIDEM programme (Illiffe et al., 2015) involved different advisory groups for each of its studies. Similar to the ICONS study, two members of the HoST-D small reference group also attended each Programme Steering committee. Furthermore, for continuity, this programme sought to involve a lay member of the ICONS programme both in the small reference group and as a co-investigator. This highlights how the HoST-D Programme clearly integrated and continued elements of good practice public involvement to strengthen research methodology.

There are few limitations to this patient and public involvement element. Members of the small reference group do not include people from an ethnic minority background, although carers were

recruited from Uniting Carers and from groups meeting at The Brain Charity in Liverpool without any inclusion or exclusion criteria. Having group members with a mix of ethnic backgrounds would have potentially highlighted additional issues surrounding home support. However, the small reference group is relatively representative in that it includes both current and former family carers, as well as people with dementia themselves, whilst one carer has also previously worked for DeNDRoN. One weakness, as well as strength, is the continuity of the members of both groups. Particularly for the small reference group, it is beneficial for carers, and people with dementia, to meet the same members at each session, which we have achieved with several members having participated before the programme grant was funded. However, due to the nature of the disease, and due to the associated caring difficulties, some carers have dropped out of the group since its first meeting in 2011. To counter this short fall, new carers and people with dementia have been recruited throughout via the same mechanisms, similar to the ICONS study (Thomas et al., 2015).

Conclusions

This paper reports on the recruitment and impact of patient and public involvement in the first two and a half years of the HoST-D Programme, and can provide guidance for future public involvement on elements of good practice. On Tripp's (1998) spectrum of working together in research with service users, the HoST-D programme gravitates around the centre of shared control, by conducting a co-operative approach in which researchers decide about the research whilst considering the opinions of users. Involving carers and patients both face-to-face and virtually to shape both the design and methods of data collection has proven an invaluable source of knowledge to adapt studies of the programme better to the real-life experience of patient and public involvement members. In the second half of the programme, patient and public involvement members will become gradually more involved in shaping the analysis and discussion of research findings, thus involving members of the public in all aspects of a research programme.

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Anthony J Hodgson is a former carer who was the full-time carer for his mother for 20 months living at home with mixed Alzheimer's disease and vascular dementia until she died from heart failure.

David Britt, PhD, is a stroke survivor with extensive experience of performing and promoting PPI in research and the training of health/social care professionals; he has been an observer, rather than carer, of several friends and family members succumbing to dementia.

Paul Clarkson, PhD, is a Research Fellow, Personal Social Services Research Unit, University of Manchester and Senior Fellow, National Institute for Health Research (NIHR), School for Social Care Research. He has undertaken and managed applied health and social care research in the fields of long-term care and mental health, dementia support, assessment interventions, policy and programme evaluation and health economic evaluation.

