Promoting co-production in the generation and use of research evidence to improve service provision in special care dentistry

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Promoting co-production in the generation and use of research evidence to improve service provision in Special Care Dentistry

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Introduction

Special Care Dentistry (SCD) provides holistic oral service provision for people with complex health and care needs.[1] These can include physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of these factors. As a result, the remit of SCD is broad and covers a heterogeneous population group. The level of disability within these population groups can also vary and a proportion of people will have multiple and overlapping impairments and/or medical conditions.[2] From a clinical perspective, it can often require "a holistic approach that is specialist led in order to meet the complex requirements of people with impairments".[3] It can also require a highly tailored approach, where the individual's clinical needs are carefully considered alongside the patient's expressed and wider medical, health and care needs.

Given the importance of these elements, it could be argued that it requires a more considered approach to the generation and use of research evidence. This is challenging as the academic literature for this heterogenous population group is not as mature as it is for those without disability and impairment. Over the last ten years, very few large-scale trials or studies have been undertaken in SCD.[4] Currently, there is only one trial that is looking at the effect of a high fluoride toothpaste in a potentially relevant population group, but this is likely to only form a small proportion of those that will be eventually recruited.[5] Equally, the role of context in oral care for people living with disability and impairment is key. An intervention or approach that might work with one patient, may not work with another, given the need to account for other personal, clinical, emotional, medical and environmental factors. This poses a challenge, as we know in the broader literature that there is generally "not enough contextual information provided to transfer the results from the trial setting into other settings".[6] The role of context can also be stripped out further by the process of evidence synthesis. As Northridge & Metcalf highlight, there is a "need to extract the core issues from the context in which they are embedded in order to better ensure that they are transferable across settings".[7] As a result, this paper explores a number of possible research methods that may better reflect the diversity and challenges of this population group, where the emphasis is placed on co-production and co-design i.e. where research is carried out *with* evidence-users "rather than to, about or for them".[8]

Importance of co-production

Understanding evidence-users' needs and the challenges of improving health and well-being is important.[9] Greenhalgh *et al.* argue that the best way to ensure that evidence is used is to co-create knowledge, drawing on the principles of co-production.[10] As Langley *et al.* highlight, co-production in this sense adopts an inductive paradigm of partnership working, positioning research as a creative enterprise that has human experience at its core, whilst paying attention to the quality of relationships within the resulting partnership.[10,11] Using facilitative methods, this approach is argued to bridge the gap between knowledge producers and knowledge users and would appear to offer some promise for SCD.[12]

Inherently, co-production and co-creation challenges pre-determined, structural and often unstated assumptions around power and helps to ameliorate epistemiological injustice i.e. it challenges just who is allowed to control the knowledge agenda.[13] As Langley *et al.* highlights, each stakeholder group (e.g. people with disability and/or impairment, clinicians, commissioners and researchers) will bring "different cognitive and emotional representation on *[an]* issue, shaped by different experiences and interests".[14] As a result, "a shared understanding of the nature of research and potential contributions to the research process has *[….]* to be considered within a dynamic context of different stakeholders' mental models, which can be used to deconstruct and advance the knowledge problem towards potential solutions".[14,15] This paper will discuss three approaches to co-production in three key areas: 1) Developing the research agenda; 2) Developing the intervention; and 3) Developing measures for evaluation. Each will be detailed briefly to elaborate on an earlier paper, using examples from on-going work in the area.[16]

1) Developing the research agenda

Priority Setting Partnerships (PSPs) are based on a consensus methodology and were developed initially by the James Lind Alliance to determine the most pressing research issues for any given population group. More specifically, they "promote discussion about how patients, clinicians and policy-makers should respond to uncertainties about the effects of treatments".[17,18] PSPs use a modified Nominal Group Technique which builds consensus across a range of stakeholders, ensuring the narratives of knowledge users (patients, clinicians and commissioners) are heard alongside those of knowledge producers (researchers).[19] As such, they help to ensure that research agendas are built on the needs of the former, rather than being dictated by the latter.

One example of this approach is the on-going PSP being undertaken by the NIHR Specialty Leads in oral health across the United Kingdom (UK).[20] The aim of this PSP is to "identify the unanswered questions related to Oral and Dental Health from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important". One extension of this approach would be to run a PSP specifically for the population groups cared for by SCD, as the careful and thoughtful use of creative approaches can allow people (like many patients in SCD) who are normally excluded from such activities to be heard. A similar approach for dependent older people was piloted in 2015 in both the UK and The Netherlands.[21,22] A summary of these two PSPs has recently been reported and the outcomes framed using Maxwell's taxonomy on quality.[23] Key stakeholders were asked to explore a series of stem questions for discussion and present their views, which were discussed in four separate groups (users of services, carers of users of services, clinicians and care home staff). A shared ranking exercise was then undertaken after further structured small group discussions. Based on the Nominal Group Technique, each group took part in a facilitated discussion to identify key local priorities, which are provided in detail in the three published papers.[21-23]

2) Developing the intervention

As highlighted by Langley, "design is both a practice and a process".[11] Design helps to make ideas tangible, develop practical and attractive propositions to evidence-users and is particularly suited to complex, ill-defined, involving stakeholders with different perspectives.[24,25] Co-design has an emphasis on process, where facilitation and co-creation brings different participants together to elicit and share their experience and perspectives.[26] Co-design recognises that stakeholders can bring both explicit and tacit knowledge and that working together in a group can help surface the latter and create new shared meaning that remains visible to all stakeholders through-out the process (given the "on-going physical presence of the prototypes").[11]

One relevant example here is the use of "Experience-Based Co-Design" (EBCD). In a NIHR funded study, researchers from Manchester, Bangor and Northumbria Universities are developing a STroke friendly Oral health Promoting (STOP) toolkit to improve oral self-care practices after discharge from hospital stroke services. Dental disease is highly prevalent in people with stroke and there is growing evidence of a potential shared inflammatory pathway.[27] People who have suffered from a stroke have higher levels of both dental caries and periodontal disease and common risk factors such as smoking.[28] Survivors of stroke tend to have fewer teeth, compared to the rest of the population and often wear dentures.[29]

Xerostomia is common due to stroke related medication, which can further significantly increase the risk of tooth decay, periodontal disease, oral infection (e.g. oral thrush) and impact negatively upon wearing dentures.[30] In turn, poor oral health has been linked with important sequelae of stroke, such as aspiration pneumonia, reduced quality of life and poor nutritional status.[31]

EBCD is an approach that puts users at the centre of the design process by first capturing their experiences of care and then uses summaries of these experiences to develop new interventions or pathways.[32,33] In the STOP toolkit study, researchers are first using qualitative interviews to understand the dental care experiences of stroke survivors, how they manage oral self-care practices, the context of the proposed intervention and what 'ideal' would look like. These experiences are being captured on video and then a trigger film will be created to relay 'touch-points' (points in the interview that are imbued with affect or that have an identified 'key-ness'), in readiness for the design stage.

At the design stage, evidence-users (stroke sufferers, their carers, clinicians and commissioners) and evidence-producers will be brought together in four stages to develop the toolkit. The facilitators of the EBCD workshops will collate the expressed needs of stroke patients, along with their preferences and contributions. These will be represented on wall charts and flip-charts to co-create, in real time, a thematically organised map of the group's thoughts, including important areas to aid in the development of the toolkit. The information will then be photo-documented and used to inform the toolkit's content (e.g. education, information provision, sign-posting) and its format (design, layout, accessibility and availability). These will then be based on APEASE criteria (Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects/safety and Equity).[34]

3) Developing measures for evaluation

Using co-production to develop the research agenda and to design new interventions are two important areas that are of potential relevance for SCD. Another important area where co-production is important is in determining the types of outcome measures that are used when we evaluate the effectiveness of interventions, based on an experimental or quasi-experimental design. As highlighted by Kirkham *et al*., there is "growing recognition that insufficient attention has been paid to the outcomes measured in clinical trials, which need to be relevant to health service users *and other people making choices about health care if the findings of research are to influence practice and future research*".[35] As a result, Core Outcome Sets, which account for the views of evidence-users is increasingly being

recognised as an important step-forward. Recent standards have been published to guide the development of COSs (COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN); and Core Outcome Set–STAndards for Reporting (COS-STAR) Statement).[33,36] The COMET (Core Outcome Measures in Effectiveness Trials) initiative brings together people interested in the development and application of agreed standardised sets of outcomes, and holds an online database of planned, ongoing and completed work.

One example here that is relevant for SCD, is the study being run by researchers from Queens University Belfast, alongside Bangor, Glasgow and Newcastle Universities and University College London: "DEvelopment of a Core outcome set for orAl health services research involving DEpendent older adults (DECADE)".[37] This study will build on the PSP identified above, which was used to set the research agenda, alongside an Effectiveness Practice and Organisation of Care Cochrane review.[38] These will be used to develop an initial set of opening questions for qualitative interviews with dependent older people, their carers, care-home staff, clinicians and commissioners of NHS services.[20] The interviews will then be transcribed and undergo thematic analysis. At the consensus stage, the different stakeholders will be asked to score each outcome from a long list of identified outcome measures gleaned from the systematic review and the previous stages of the process. This will be undertaken in stages, similar to processes already utilised in dentistry.[39] Subsequent approaches for the final selection of the COS include the scale proposed by GRADE: 1 to 3 signifies an outcome of limited importance, 4 to 6 important but not critical, and 7 to 9 critical.

A number of rounds across multiple stakeholder groups will be held, using the GRADE criteria. This will enable the research team to summarise the responses and feed this back to the stakeholder groups to produce a refined version. To be consistent with the approach, an outcome will be included in the COS if more than 70% of the stakeholders score the measure between 7 to 9 and if fewer than 15% of the stakeholders score it as 1 to 3. Equally, consensus that an outcome is not included in the COS will be defined as 70% or more scoring it as 1 to 3 and fewer than 15% scoring it as 7 to 9.[40]

Summary

Given the complex requirements of people with disability and impairments and the holistic and tailored approach to clinical management that is commonly necessary, it would appear that co-production has much to offer SCD. Three brief examples have been provided that outline how such an approach may help in the generation and use of research evidence. All

adopt an inductive paradigm of partnership working, positioning research as a creative enterprise that has human experience at its core. Using facilitative methods in the development of research agendas, intervention development and outcome measurement helps to narrow the gap between knowledge producers and knowledge users, whilst heralding an approach that ensures that the experiences and knowledge of all stakeholders are considered equally.

In the first example, issues around power were addressed by using different stakeholder groups to set the initial priorities at separate meetings. These were then refined at a final meeting which contained representatives of each of these groups, but chaired by a patient representative to ensure the views of users of services were given weight. In the second example, the design of the intervention will again be considered by individual groups during the first iteration of the toolkit, with stroke patients themselves driving the note-making and collation process. Clinicians and commissioners of care will input into the design stage in separate groups undertaken concurrently, but again, the pooling of the different ideas from the different groups will be steered by stroke patient representatives in the final amalgamated group and the subsequent meetings. The use of patients in the development of COSs is now fully recognised and the explanatory document accompanying the COS-STAR statement has multiple references to end users of services to ensure that their views are represented.[41] In Rheumatology research, the explicit inclusion of patients in the development of COS has "significantly influenced outcome research in the field […] identifying new domains that are important for patients, and provided the patient perspective".[42] Overall, this has "led to wider patient involvement as *partners* in research" and now is being used in 81% of trials on the ClinicalTrials.gov database, two pertinent goals for research in SCD.[42,43]

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