

Co-production in Action

NUMBER TWO



What is Co-Production?



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Co-production in Action: NUMBER TWO

Acknowledgments

We, the project team, would like to thank everyone who has been involved in the development of this publication. Special thanks to our contributors to this issue and to Ruth Richardson, a public member on the advisory group at INVOLVE, for reading through and commenting on drafts of this publication.

Introduction

Welcome to the second in our series of three publications highlighting co-production in action. This series of publications build on our earlier work [Guidance on co-producing a research project](#) (1), in which we outlined the key principles and features of co-production. Our Co-production in Action series provides examples of how these key principles and features find expression in practice. The series is our response to feedback we received, from readers of our initial guidance, which revealed a demand for practical examples of co-produced research. You can find the first in our series (2), along with a complementary webinar here: <https://www.invo.org.uk/current-work/co-production/>

About the examples

In this publication there are three examples of co-producing research. The first example is from Nursing, Midwifery and Allied Health Professions Research Unit (Glasgow Caledonian University), in which stroke survivors, carers, physiotherapists and educators were involved in an update of a Cochrane systematic review relating to physiotherapy after stroke. A systematic review is a research method in which international literature is brought together to answer a specific healthcare question. And Cochrane is an international organisation which produces systematic reviews. The second example involves a partnership between University of Stirling, Age Scotland, and The Life Changes Trust in which community researchers worked with University researchers to research quality of life in later years. Finally, we have an example from NIHR Devices for Dignity (D4D) MedTech Co-operative (hosted by Sheffield Teaching Hospital NHS Trust) in partnership with Lab4Living (Sheffield Hallam University). In this example children and their families worked with key opinion leaders from the healthcare, academia and industry to 'incentivize the development of new breakthrough innovative prosthetic products for the NHS.'

We hope that the examples in this publication help increase understanding of how key principles and features of co-production can find expression in practice, inspire readers to embark on their own co-production journeys, and spark debate about the various challenges involved in co-producing research. And we hope that these examples can play a role in helping bridge the gap between research and policy rhetoric around co-production and the reality of implementing co-production in practice (3). Please do let us know what you think.

The key principles and features of co-producing a research project are referred to throughout this publication and so it is worth reiterating them here:

Key principles

Sharing of power – the research is jointly owned and people work together to achieve a joint understanding

Including all perspectives and skills – make sure the research team includes all those who can make a contribution

Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance

Reciprocity – everybody benefits from working together

Building and maintaining relationships – an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock potential

Key features

Establishing ground rules

Ongoing dialogue

Joint ownership of key decisions

A commitment to relationship building

Opportunities for personal growth and development

Flexibility

Continuous reflection

Valuing and evaluating the impact of co-producing research

The project team: Gary Hickey, Simon Denegri, Sam Goold, Gill Green, Doreen Tembo, Katalin Torok, Gill Wren (all National Institute for Health Research), Sally Brearley (Kingston University), Tina Coldham (INVOLVE Advisory Group), Sophie Staniszewska (University of Warwick) and Kati Turner (St George's University).

1. Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., Tembo, D., Torok, K., and Turner, K. (2018) **Guidance on co-producing a research project**. Southampton, INVOLVE
2. INVOLVE (2019) **Co-production in Action: Number One**. Southampton, INVOLVE
3. Hickey, G., Chambers, M. (2019) Patient and public involvement and engagement: Mind the gap. **Health Expectations**. 22:607-608

When referencing this guidance please use the following:

INVOLVE (2019) **Co-production in Action: Number Two**. Southampton, INVOLVE

1

SPRUCE - Stroke Physiotherapy Review Update of Cochrane Evidence

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Organisations involved in the research:

Nursing, Midwifery and Allied Health Professions Research Unit, Glasgow Caledonian University

Summary of the research:

We involved stroke survivors, carers, physiotherapists and educators (our stakeholder group) in an update of a Cochrane systematic review relating to physiotherapy after stroke. Systematic reviews are a research method in which international literature is brought together, using carefully designed and rigorous methods to answer a specified question about healthcare. Cochrane is an international organisation which produces systematic reviews which provide the highest quality evidence on the effectiveness of healthcare interventions. Cochrane systematic reviews are regularly updated to ensure that new healthcare studies are included within the summarised evidence.

We had first published our Cochrane stroke physiotherapy systematic review in 2003, and an updated version was published in 2007. Neither of these versions of the review had been co-produced. When we started planning an update in 2013 we realised that there were some important decisions to be made about the structure and scope of the review in order to make sure that it was clinically relevant and useful. We therefore convened a group of service users, carers and NHS physiotherapists to co-produce the review update with the review authors.

Our stakeholder group comprised 13 people, including stroke survivors, carers and physiotherapists working in stroke care. This group guided the project to update the review, and had responsibility for making a number of key decisions throughout the review process, including decisions about any amendments to the methods from the previous versions of the review. Key decisions about the review were primarily made at three face-to-face meetings which took place over the course of a year, and which were attended by these 13 people plus the review authors. At each of these meetings the group members debated and reached consensus on a number of key decisions relating to the review.

The group used formal consensus-making methods to reach decisions. These methods were based on an approach called the 'Nominal Group Technique'. This involved group members debating around a specific topic or decision, followed by each group member voting (anonymously) on a series of different choices relating to the review. After each decision was made, the group members agreed the next steps for review authors.

In addition to the planned meetings, the group was involved throughout the project via email and telephone. A variety of methods were used to gain feedback or comments, and reach shared decisions, on specific issues. For example, the group members read, commented on, and completed feedback forms relating to some of the studies which were being considered for inclusion in the review, contributing to decisions about whether it was meaningful to combine the results of different physiotherapy interventions. In one case, where a decision had to be made on an amended review title, all group members participated in online voting to ensure everybody had a voice in deciding which wording was chosen for the title.

What stages of your project were co-produced?

Our project was a major update of a Cochrane systematic review. We formed our stakeholder group before any work started on the review, and they were involved throughout the 12 month project. However, the key stages of the Cochrane review which were co-produced were.

- **Planning methods:** the methods of a Cochrane review are always pre-defined and published in a protocol. Before a review is updated, the protocol is re-visited and some changes to the review methods may be planned. The protocol for the review that we were updating described how studies about different approaches to physiotherapy would be brought together, and pre-stated a number of statistical analyses which would be performed to explore the results of these studies. Prior to us doing any work on the review, our stakeholder group made key decisions about the way in which studies should be brought together, and proposed new questions to be answered through statistical analyses.
- **Categorising data:** in order to bring studies investigating similar approaches to physiotherapy together, the type of physiotherapy delivered in each study had to be categorised. A new way of categorising types of physiotherapy was developed and agreed by the stakeholder group. The way of categorising types of physiotherapy informed the structure of all the statistical analyses subsequently carried out within the review.
- **Interpreting findings:** the review results, including the results of the statistical analyses, were presented by the researchers to the stakeholder group. The stakeholder group discussed and agreed what the implications of these findings were. A list of key implications for clinical practice arising from the review results were co-produced and published within the Cochrane review.
- **Disseminating findings:** a dissemination plan was co-produced, listing where the review results should be published and presented (in addition to the publication of the Cochrane review). The stakeholder group highlighted the need for a two-page summary document, and this was co-produced by researchers and the stakeholder group. Members of the stakeholder group indicated that they would like to disseminate findings through their local networks, and a powerpoint presentation was developed which could be used by stakeholder group members to present an overview of the review results.

Links to the research:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4407304/>

<http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD001920.pub3/full>

How did the key principles of co-producing research find expression in your research?

Sharing of power

We knew that there were a number of important decisions to be made prior to updating our Cochrane review. We knew that these decisions would significantly impact on how the evidence was brought together within the updated review, and could substantially affect the structure, scope and methods of the review. We pre-planned that these decisions would be made by the potential “users” of our Cochrane review: stroke survivors, carers and physiotherapists. Decisions made by our group of “users” contributed to the co-production of the review, with stroke survivors, carers and physiotherapists working in partnership with review authors and researchers.

Figure 1 (below) summarises how the nominal group technique (consensus-making method) was used in the meetings. There was a set time period for discussion around a statement or issue, followed by voting. Figure 2 (next page) shows a sample voting slip.

Figure 1: Structure of meetings using the nominal group technique

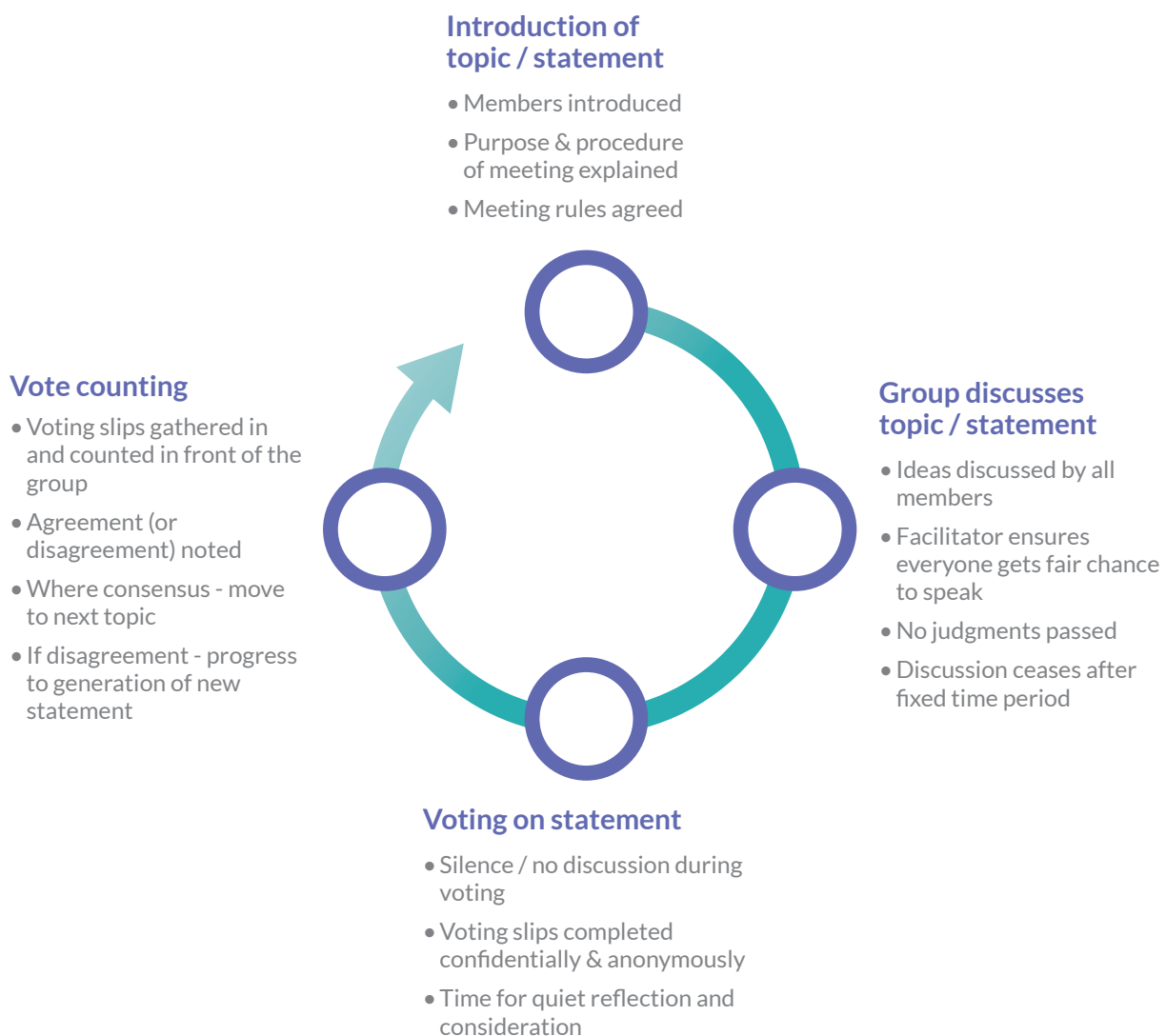


Figure 2: Sample voting slip.

A. The current categories are appropriate and clinically relevant.				
Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
1	2	3	4	5
Any Comments:				

Researchers contributed to discussions around each decision, but it was only the stroke survivors, carers and physiotherapists who got a “vote” on each of these decisions. When the group members reached a decision to alter review methods, and further information was required to enable them to develop and agree new methods, they collectively agreed the next steps for researchers in terms of what further information was required.

The consensus decisions reached by the group using this technique had a substantial impact on the Cochrane review, and on the subsequent work completed by researchers. For example, consensus was reached during the first meeting that the way of categorising different types of physiotherapy within the previous version of the Cochrane review was no longer appropriate or clinically relevant. After this decision was made, researchers asked the group members to suggest alternative ways of categorising the types of physiotherapy; group members proposed that it would be most useful if “treatment components” could be categorised. “Treatment components” were considered to be all the different techniques which could make up a physiotherapy treatment session for someone who had had a stroke; for example, muscle strengthening, balance training, or techniques based on specific neurophysiological theories. The group members asked researchers to complete a number of additional tasks to inform their next decision around how to categorise based on “treatment components”. These tasks included bringing together the written descriptions of physiotherapy treatments which were provided in a sample of the studies, and highlighting those which had similar – or different – “treatment components”. This information was compiled by researchers and shared with group members prior to the second meeting. Then at the second meeting, this information was used to inform decisions (again using the nominal group technique). The decision making at the second meeting resulted in development and agreement over a list of 27 specific “treatment components”, each with a brief written description, and each categorised into one of seven different categories (different approaches to physiotherapy). These new categories, and defined “treatment components”, formed the structure of the final Cochrane review. The physiotherapy treatment given in every research study included in the review was described using these categories and “treatment components”. The structure of all the statistical analyses, which aimed to explore if there was evidence of any particular physiotherapy being more (or less) effective, was built around the components and categories developed by the stakeholder group.

In this way, power was shared between the group members and the researchers, with clearly defined roles for both the group members and researchers. The sharing of power does not mean that people do not have defined roles and areas of responsibility. The group members had responsibility for, and ultimate control over, a number of pre-specified key decisions which were fundamental to the structure of the systematic review. The researchers had responsibility for completing the review tasks, and incorporating the decisions of the group members into the review process. While the roles and responsibilities of the group members and researchers were different in nature, there was a shared understanding that everyone was working as a team to produce a Cochrane review which was accessible and useful to the end-user.

Including all perspectives and skills

The Cochrane systematic review that we were updating was focussed on physiotherapy for people with stroke. We therefore involved stroke survivors, carers and physiotherapists. We developed a role description, advertised the opportunity widely, and invited expressions of interest and purposefully selected, aiming for diversity. To ensure inclusivity, we did not require group members to have any previous knowledge of research or systematic reviews. We highlighted that we were interested in the views of people who had a lived experience of stroke, caring or providing rehabilitation for someone with stroke.

We ensured that any information provided (whether presented at a meeting, or sent out to members) was accessible and so enabling all to contribute. For example, at our first meeting we told group members that we were assuming they had no knowledge of systematic reviews or clinical trials, and we started the meeting with a basic presentation describing what these were. When there were decisions which required detailed understanding of the physiotherapy treatments delivered in some studies, we provided the same study information to both the stroke survivor, carer and physiotherapy members of the group: we made it clear that everyone's interpretation and views were valued, and encouraged group members to ask questions where there was information that they did not understand. At times this led to stroke survivor and carer members challenging the physiotherapists on their use of language, and on the use of "physio talk", and led to agreement on shared understanding and agreed definition of terms.

Respecting and valuing the knowledge of all those working together on the research

The need to respect and value everyone's views and opinions was emphasised when the group got together. This was specifically discussed at the first meeting, and the group members were asked to propose and agree group rules which afforded equal respect and value. The group were reminded of the agreed meeting rules (see figure 3 next page) at the start of each meeting.

Our use of formal group consensus methods to reach consensus decisions meant that everybody in the group had equal power. These methods were based on the 'nominal group technique'. This technique involved first having an agreed period of time to discuss a particular topic/issue/decision. Everyone was able to contribute to this discussion, with the agreed meeting rules ensuring that everyone got a chance to speak and that no one person could dominate the discussion. After the agreed period of time was finished, the discussion was finished and all group members were silent. They were then given a paper voting slip and voted anonymously on the decision. This method of voting meant that, regardless of the views expressed during discussion, everyone had an equal say in the final decision making.

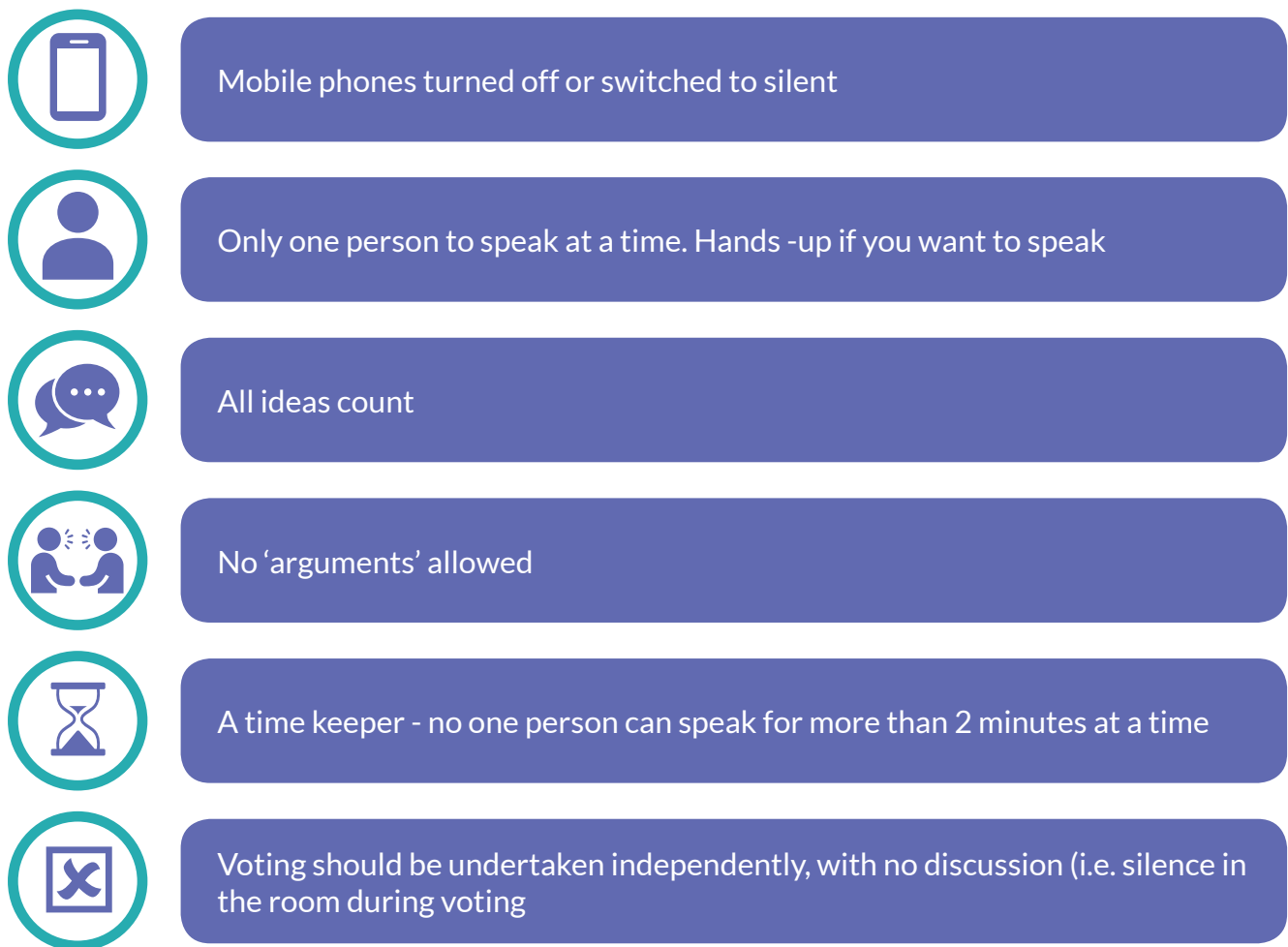


Figure 3: Agreed meeting rules

Building and maintaining relationships

Stakeholder group members did not know each other prior to this project. Time was taken for each member to introduce themselves at the first meeting. Each meeting was scheduled to start with a buffet lunch, lasting approximately 30 minutes. This encouraged group members to talk informally and to build relationships. After the project was finished, because the group members had been so enthusiastic about their involvement, we sought funding to take some of the group members to the UK Cochrane meeting, which is an annual national conference attended primarily by authors, editors, and consumers of Cochrane systematic reviews. Four group members volunteered to attend. We ran a workshop at which they shared their experiences of contributing to a Cochrane review.

Reciprocity

Our experience of involving people in this systematic review led to our work on the 'ACTIVE' project (Authors and Consumers Together Impacting on eVidencE), which aimed to help systematic review authors have meaningful active involvement in systematic reviews. The ACTIVE project led to the developing of the 'Involving People' resource. This is a 'one-stop-shop' for authors to find out best practice and practical suggestions about involving people throughout the review process; including useful resources, guidance documents, interviews about first hand experiences, and links to case studies and examples of good practice:

<http://training.cochrane.org/involving-people>

Cochrane have produced a number of webinars relating to this resource:

<http://training.cochrane.org/learning-events/learning-live-webinars/consumer-involvement>

This includes a recorded webinar relating to the SPRUCE project, and a number of related resources: <http://training.cochrane.org/resource/involving-consumers-cochrane-reviews-learning-active-project>

A podcast describing our Cochrane review is available here:

<http://www.cochrane.org/podcasts/10.1002/14651858.CD001920.pub3>

How did the key features of co-producing research find expression in your research?

Establishing ground rules

At our first group meeting we established ground rules. We discussed various rules and the importance of valuing and respecting all opinions, and we asked group members to propose and agree a series of rules. For example, the group decided that, to make it easier for everyone to get their voice heard, no-one would be allowed to “jump” into the group discussion without first raising their hand - a group facilitator ensured that each person with a raised hand was given an opportunity to speak. Furthermore, the group decided that, to avoid one person dominating any aspect of the discussion, no person would be allowed to talk for more than two minutes before the discussion was moved to the next person - the group facilitator acted as a time keeper.

Joint ownership of key decisions

We had pre-planned (at the funding application stage) which review-related decisions we would hand to the group members. For each of these decisions, there was a period of discussion to which everyone was able to contribute (stroke survivors, carers, physiotherapists, researchers and review authors), followed by a formal voting process which only stroke survivors, carers and physiotherapists were able to take part in. This meant that knowledge and ideas were exchanged and discussed, with a range of people contributing their ideas and expertise, but the final decisions were taken by the stroke survivors, carers, physiotherapists.

For example, group members spoke about the use of complementary therapies (such as acupuncture) alongside more traditional physiotherapy treatments, and how this might be of interest to some stroke survivors. In response, researchers went back to all of the studies included within the systematic review and noted whether or not study participants may have been receiving acupuncture in addition to (or as part of) the study treatment. In this way we ensured that the group members were aware that issues that they raised were listened to and acted on, and they knew that their contributions led directly to an impact on the final review.

A commitment to relationship building

Our approach embraced the principles of coming together in equal, honest and respectful relationships. Our group rules (see figure 3) made sure that everyone got equal opportunities to contribute their thoughts and ideas. All thoughts and ideas were captured by the research team, and during meetings researchers ensured that they responded to all ideas, and always ended a period of discussion by clarifying what actions would be taken in response to the points discussed. For example, during one discussion a group member raised the issue that stroke survivors may respond differently to physiotherapy treatments depending on the length of time since the stroke. In direct response to this, researchers confirmed that they would run additional statistical analyses to explore this issue, and reported on this additional analysis at the next meeting.

Confidentiality was respected when individual group members contributed thoughts and ideas by email; researchers always shared summaries of the content of email submissions with the whole group, however this was always done anonymously.

One of the group members said when reflecting at the end of the process: “...I have taken part in quite a number of things of this nature over the past 20 years and this is the first time that I have really felt that it has been successful and that I have been listened to.”

Flexibility

While the project was pre-planned - and the meeting dates of the stakeholder group were fixed in advance - the decisions made by the group members led to significant changes in the activities that researchers had to complete between meeting dates. The funding application which supported this project highlighted that project decisions would be made by the stakeholder group, and that this would require flexibility. It was stated that four key project decisions would be made by the stakeholder group, and that these would inform the final project activities and outcomes. For example, it was stated that the stakeholder group would decide on a revised structure for the updated review, and a range of alternatives were given as examples in the proposal – these included the possibility of dividing the existing review into two reviews, or expanding or changing the scope of the existing review. Clear boundaries were written within the funding proposal in order that the project would remain feasible within the fixed project timetable – for example, the review would remain focussed only on physiotherapy treatment for people with stroke, and would only include randomised controlled trials. The researchers found that they needed to be flexible in managing their workload which occurred as a direct response of the decisions made by the stakeholder group. For example, at the end of the first meeting, group members reached the decision that the way the review had previously been structured should be changed. They suggested that an entirely new way of categorising (describing and grouping) different physiotherapy treatments should be used. The information which researchers had taken from the studies previously included in the review was not enough to fully inform the proposed new way of categorising the treatments. In response the researchers went back to all the original studies and took out more details about the treatments. This additional information was then sent out to all the group members prior to the next meeting, so that at the next meeting group members could make a fully informed decision. In this way, researchers responded in a flexible way, doing substantial amounts of additional work in order to provide the stakeholder group members with the information that they requested. The researchers had to put additional time into the project at this stage, adjusting their daily workplans and activities in order to respond to the requests of the stakeholder group in time for the next scheduled meeting.

Five key learning points :

- Co-production of a systematic review can make reviews more clinically relevant and accessible.
- Stakeholders can play a key role in making shared decisions about the structure, scope and methods of a systematic review.
- The nominal group technique can be used to reach clear consensual decisions as part of research co-production. The use of the anonymous vote ensures that everybody in the group has equal power in the decision making process.
- Fixing all meeting dates prior to identification and recruitment of group members can help ensure that potential recruits are all available for all meetings.
- Agreeing on ‘meeting rules’, which include strategies aimed at making sure no one person can dominate the discussion, can help ensure that all group members can participate equally.

Useful references for co-producing research:

Pollock, A., Campbell, P., Struthers, C., Synnot, A., Nunn, J., Hill, S., Goodare, H., Morris, J., Watts, C. and Morley, R. (2019) Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. **Journal of Health Service Research & Practice** 24(4); 245-255. Doi: 10.1177/1355819619841647.

Kayes, N., Martin, R., Bright, F., Kersten, P. and Pollock, A. (2019) Optimising the real-world impact of rehabilitation reviews: increasing the relevance and usability of systematic reviews in rehabilitation. **European Journal of Physical and Rehabilitation Medicine** 55(3), DOI: 10.23736/S1973-9087.19.05793-9

Pollock, A., Campbell, P., Struthers, C., Synnot, A., Nunn, J., Hill, S., Goodare, H., Morris, J., Watts, C. and Morley, R. (2018) Stakeholder involvement in systematic reviews: a scoping review. **Systematic Reviews**, 7(1), pp. 208, DOI: 10.1186/s13643-018-0852-0

Pollock, A., Campbell, P., Struthers, C., Synnot, A., Nunn, J., Hill, S., Goodare, H., Watts, C. and Morley, R. (2017) Stakeholder involvement in systematic reviews: a protocol for a systematic review of methods, outcomes and effects. **Research Involvement and Engagement**, 3, pp. 9, DOI: 10.1186/s40900-017-0060-4

Pollock, A., Campbell, P., Baer, G., Choo, P.L., Morris, J., and Forster, A (2015). User-involvement in a Cochrane systematic review: using structured methods to enhance the clinical relevance, usefulness and usability of a systematic review update. **Systematic Reviews** 2015; 4(55). DOI:10.1186/s13643-015-0023-5

Involving People in Systematic Reviews Lab. <https://www.researchgate.net/lab/Involving-People-in-Systematic-Reviews-Alex-Pollock>

2

A Good Life in Later Years

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Ro Pengelly, Community Researcher

Full research team: Jim Aitken, Pek-Yeong Berry, Daisy Cameron, Tish Chalmers, George Clunie, Diana Findley, Grant Gibson, Joan Gibson, Amanda Graham, Kate Graham, Ian Gourlay, Corinne Greasley-Adams, Rog Harrison, Murial Knox, Jane MacPhair, Janice Mason-Duff, Fiona McCall, Vikki McCall, Suzanne Murdoch, Ro Pengelly, Jane Robertson, Helen Ross, Kim Shepherd, Geri Sinclair, Betty Skelton, Kim Strachan, Sheila Thorburn, Eileen Wallace and 6 community researchers whose identity remains anonymous.

Organisations involved in the research:

University of Stirling, Age Scotland, The Life Changes Trust

Summary of the research:

In May 2016, the University of Stirling received funding from the Life Changes Trust to work alongside Age Scotland, to research quality of life in later years. The research, which later became known as the 'A Good Life Project' aimed to deepen our understanding of the topic by moving beyond restrictive views of quality of life and adopting a holistic approach to health and well-being. The ethos was to ensure that health and social care matters were not isolated from housing, transport or other issues that, from the older person's perspective, contributed to quality of life.

The research had a further aim of using an innovative approach that would help counter stereotypical images of getting older. Co-production across multiple sites, with individuals over the age of 50 years positioned as researchers within their own communities (community researchers), was at the heart of this approach. The research recognised and demonstrated the talents and creativity of older people and how they can be enabled in a way that would empower communities to lead on local improvements. The project was designed to support meaningful partnership working and to demonstrate that co-production is possible on a large scale, across multiple sites. The project team consisted of the 30 community researchers working in five geographically based teams (Aberdeen, Galashiels, Kilmarnock, Perth, and Stirling), who worked alongside four university-based researchers and two representatives from Age Scotland.

Each of the geographical teams met on a regular basis with university researchers and the Age Scotland representative. Locating teams in geographical areas was initially important to identify local variations in experience and knowledge, as well as in facilitating local connections between the project team members and with external groups and organisations. These meetings would support the formal research process and allowed the space for researchers to: make unified decisions about the direction of the project; share knowledge, training and support on research processes; and explore the data gathered to draw findings and implications. As the research progressed, and in response to requests, full project meetings were organised in Stirling.

Between meetings, the project team were all involved in gathering data through three methods. These methods had been identified by the university team prior to the project being funded and community researchers being recruited. However, flexibility was built into the process to ensure that community researchers were able to mould the approaches to suit their preferences and knowledge of what would work within their communities. There were three phases to the research.

In phase one, the project team set out to undertake a visual analysis of what makes a good life in later years. Researchers were able to use a one-page questionnaire to capture input from older people on what was important to quality of life as they aged. Researchers were then able to take pictures of these aspects, locate existing pictures they had, or to take an image of a creative piece of work that represented the topics.

The images (127 in total representing the views of 67 older people) were analysed to highlight the key themes emerging. They were also used as a tool in the second phase to stimulate discussion around A Good Life in Later Years, and would be available for use in presentations and publications in disseminating the findings from the project.



Phase one identified a number of key topics that would be used to guide categorisation of data gathered in phase two. In phase two, each geographical research team designed their own topic guides for focus groups (small groups of people who discuss a particular topic or topics) and decided on how focus groups would be undertaken.

Community researchers jointly conducted 12 focus groups with university researchers, gathering the views of a further 66 older people. The findings from the focus groups were analysed during group sessions, using a process of coding and reflection. These findings, alongside the findings from the visual analysis in phase one, were reflected on as the team co-designed a questionnaire that was distributed across Scotland.

A total of 748 questionnaires were returned. Topics addressed included health, transport, housing, work and retirement, volunteering, preparing for end of life, social attitudes, communities, services, hobbies and pastimes, learning and education, money and financial resources, social relations and friendships, environment, independence and choice, belief systems, and technology.

A celebration of the project was held at the Scottish Parliament in September 2017. Since then the research team have continued to work together on subsequent projects and in the development of a toolkit for geographical communities and communities of interest to identify and prioritise where and how they can support A Good Life as they age.

Links to the research:

<https://www.lifechangestrust.org.uk/sites/default/files/publications/Good%20Life%20in%20Later%20Years%20FINAL%20NOV%2017.pdf>

www.agoodlife.scot

What stages of your project were co-produced?

This covered: method refinement (including development of research tools), recruitment of participants, conducting fieldwork, analysing data, dissemination. Training sessions were also co-designed.

How did the key principles of co-producing research find expression in your research?

Sharing of power

Consensus decision-making was at the heart of the project. As far as possible, all key decisions about the research process were made through open and transparent discussions with community and university researchers. This process was facilitated by meeting regularly (normally every two to three weeks) with each project team and through ongoing communication outside of those meetings. Coming to a consensus with 30 community researchers and four university researchers was challenging as individuals came to the project with varying and diverse perspectives. This was, to a degree, managed by initially working within small teams of between four and eight people, with each team having the power to shape how the research would be taken forward within their communities. This meant variations between teams, for example in the design of focus group structure/topic guides, which were created according to the key areas emerging from the first phase of research conducted by that research team.

Community and university researchers jointly made decisions about the research project as it progressed, with the project lead making a final decision if no consensus could be agreed.

At its most optimum level, co-produced research will have involved discussion amongst all parties from the development of the research idea, through the funding process to completion. However, such discussions only occur once established relations between co-researchers have been created.

In our project there was no funding available to support the recruitment of community researchers and the establishment of working relations between co-researchers, nor were there funds to support out-of-pocket expenses for those joining in team meetings ahead of the project being funded. Effectively this meant that the funding proposals were created and submitted by the university researchers (without comment from community researchers) and as part of that proposal there was a need to specify the research processes that would be followed.

We faced a challenge of how to share power in the research design in the absence of pre-project funds facilitating integrated working and where there was a need for a response to tender that clearly required a research approach to be specified. As a workable compromise, we built in some flexibility that would enable the sharing of power once the project was underway.

We specified identifying data through three approaches (i.e. visual methods, focus groups, and a survey) but were transparent about the fact that the precise ways in which this would be conducted would be determined by the community researchers. It is worth noting however that sharing of power was transitional in nature during the project. We were required to submit our

project proposal to a University ethics committee ahead of recruiting community researchers and this covered the first two phases (visual methods and focus groups). The overall time frame for the research did not allow for a further submission to the ethics committee after community researchers had been recruited.

In phase one (visual methods) three possible approaches to gathering data had been approved to allow for some choice in the direction taken. Approvals for phase two allowed greater flexibility as it was acknowledged in the ethics submission that the participants and the topic guides would be decided by the teams. However, in order to progress on that basis it was necessary to speculate who the anticipated participants might be and the topics that may be covered. This of course was supplemented with a statement indicating further ethical approvals would be sought if the anticipated diverged from the actual. The final phase, in which no initial ethical approval had been sought, allowed for the greatest scope in sharing of power with the full direction being decided equally by community researchers and university researchers. To that effect, as the project advanced, the extent to which power was shared grew, but at all stages there was some degree of choice and flexibility for community researchers to shape the research direction.

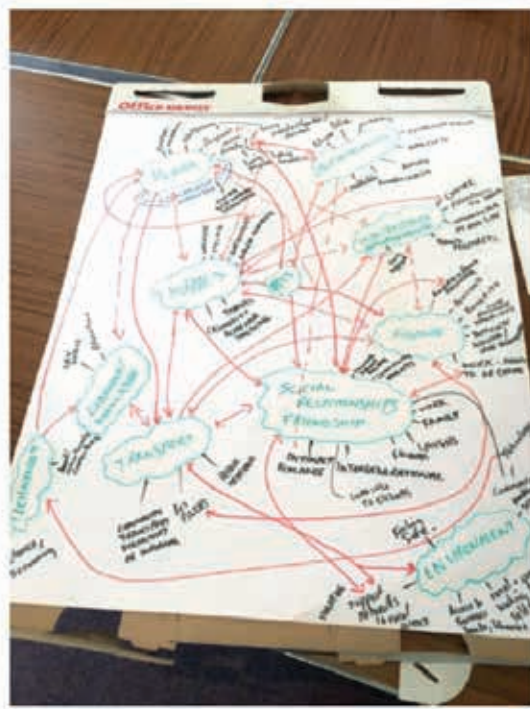
Including all perspectives and skills

It was essential that the project was structured in a way that the multitude of diverse perspectives could be integrated into our understandings of A Good Life and could also inform the analysis of information gathered. The volunteer status of community researchers helped to ensure that all perspectives were treated equally. This fostered a culture where, in the absence of an employer/employee relationship, community researchers would feel at ease to express their understandings and to challenge the views of university researchers. Inclusivity and diversity were enabled through local research teams having the power to modify the process to suit different communities.

As the teams were located in different regions in Scotland, the project was able to ensure that local voices and regional variations were captured. Locally-based teams were also more easily able to make connections with communities that may be under-represented in traditionally designed research projects. For example, researchers from one Chinese community were able to support us in hearing the voices of others within that community. Similarly, we were able to incorporate people living in lower socio-economic areas because of the existing connections to these communities that researchers had. Other co-researchers had links to organisations supporting people living with dementia and were able to use their skills and experiences to make the research more accessible for people living with dementia. A real strength of this approach was the opportunity to learn from community researchers' knowledge, experience and skills, and to tailor the research locally in a way that it became accessible and more diverse in its engagement with participants.

Respecting and valuing the knowledge of all

It was important that the knowledge contributed by each researcher – community researcher and university researcher - would be respected and valued equally at all stages of the project. With an interpretive element to it, qualitative research methods are open to being shaped by the knowledge and experiences of those undertaking the research. In this project we were keen that the knowledge of both university and community researchers should therefore inform the analysis undertaken and, subsequently, the findings reported. Therefore, data gathered by the teams was analysed by the teams. For the visual methods this included discussing each of the images and the themes they represented before creating visual maps of the key concepts that were emerging.



For focus group data, this included a session whereby teams went through the transcripts, extracted quotes that captured what participants were saying was important to A Good Life in Later Years, and coded these under the thematic framework identified from the first phase of the research (visual analysis).

The survey data was analysed by university researchers using SPSS (Statistical Package for the Social Sciences – a software package that enables analysis of statistics), but community researchers had the opportunity to suggest additional questions and tests to be conducted on the data. Reports were prepared separately for each of the different methods and a meeting was held where community and university researchers jointly decided on the key messages and findings emerging from each of the themes covered. It was these that were reported in the final report for the project. This approach ensured that the knowledge and expertise of all researchers not only informed the collection of data but also the findings generated and reported.

There were some challenges, in particular overcoming the pre-conceived ideas of research and power relations that exist in more traditional methods of research. In the earlier stages of the project some community researchers felt that university researchers would be better placed to inform and make decisions on the approach to be taken going forward. Other community researchers, who had never been involved in this type of work previously, were less comfortable and confident in sharing their perspectives. It was essential to invest time and practice in supporting a culture that overcame these challenges. Working in smaller teams (of between four and eight people), adopting a supportive and less formal approach that valued personal reflection, listening and acting on suggestions made, and reiterating the model of co-produced research being adopted in the project, were all central in overcoming these challenges.

The project also recognised the skills and assets that community researchers already had. For example, some of the researchers had previously been involved in medical professions and others had personal or professional experience of supporting or caring for people living with dementia. They were actively able to contribute to dementia awareness training of other team members and in ensuring that the methods used were accessible and inclusive for people living with dementia. Some community researchers had been involved in scientific professions and were encouraged to provide insight into survey sampling and to support others in the interpretation of the findings from the surveys. They were also able to provide insight into some of the challenging practicalities that might emerge whilst working in a university environment. Other community researchers had strengths in networking and experience in committees/organisations with a view to shaping policy. The knowledge and skills of these researchers was vital in creating and shaping strategies for dissemination of findings. The range of assets and skills brought to the project was extensive and varied, and researchers were encouraged to use these to inform the direction of the project and to support the personal development of other researchers.

Having small research teams (of between four and eight community researchers) in different geographical areas of Scotland, meant that it was easier to respect and value knowledge of a wider range of communities.

Including different forms of data collection enabled different preferences for communication of knowledge. Community researchers were able to engage or disengage with each of the methods in a way that suited them most. This meant that some community researchers opted out of being part of collecting visual materials, whilst others refrained from the opportunity to engage in collecting data through focus groups. Some engaged more with the analysis of the visual methods, and others with the analysis of focus groups and reflection on the survey findings.

At the very first meeting with community researchers there was an open and transparent discussion about the importance of capturing different perspectives and valuing the knowledge that each and every community researcher would bring to the project. Each team was asked to create ground rules that would apply to their team and would help them not only to ensure that all knowledge contributed was valued but also to ensure that the teams would work effectively. These ground rules included: encouraging individuals, who were quieter, to contribute their perspective; everyone having the responsibility to prevent anyone dominating discussions; recognising and respecting that there may be different perspectives. Further information is included under the section 'Establishing ground rules'. All members of the team had a responsibility in ensuring that ground rules were adhered to. They would use their own skills and methods to manage where there was divergence from this – with humour often being used to challenge, in a less confrontational manner, dominant voices and introduce alternative perspectives.

Reciprocity

In this project, community researchers received no financial remuneration for their time but were reimbursed for fair out of pocket expenses. The project also offered community researchers other potential benefits. Small geographical teams provided opportunities to meet others within the local area, further friendships and widen social networks. Training provided during team meetings allowed people to expand their skills, and also to share their knowledge and experience with others. The project provided a space for skills and experiences to be respected, valued and to be embedded into new knowledge development. It was designed with a view that that knowledge would be taken forward directly into policy development and practice. For example, in working

with Age Scotland, information discussed during meetings was taken forward and informed their directions and publications. In addition, the project provided funding to attend networking events (with other community groups), conferences and dissemination events. Access was offered to University IT and library facilities and their work as researchers were covered by the University's public liability insurance.

Whilst there were many reciprocal benefits offered, it was acknowledged that there would be variation in the elements of the project that would be attractive to individuals. By having a range of benefits embedded, it was hoped that there would be diversity in the community researchers recruited. In practice, community researchers did join the project for a range of reasons, for example, to get to know others in their community, to use skills that they had previously developed, to learn new skills and to make a difference and to raise awareness of different issues.

The range of methods allowed for expansion of skills and knowledge. For example, some community researchers had never been photographers or used digital cameras and this project provided the opportunity to learn about these through both the formal training offered and through informal interactions with other community researchers that were experienced in this.

Building and maintaining relationships

Regular team meetings within local areas supported the building of relationships with others. These meetings were full day meetings, with informal networking promoted during coffee on arrival and over lunch. The meetings had a structured content of activities to be completed but were informal in their tone and structured in a way that would see team members bond with each other. Informal discussions and reflection on personal experiences, humour and laughter were frequently experienced alongside completing the structured activities. Structured activities included making decisions and plans for the research going forward, research training and analysis of data. Beyond the meetings, connections with the wider community were strengthened or widened as community researchers undertook research activities in their own communities. Relationships were further forged by e-mail, and by openly inviting comment on draft reports and other project documents.

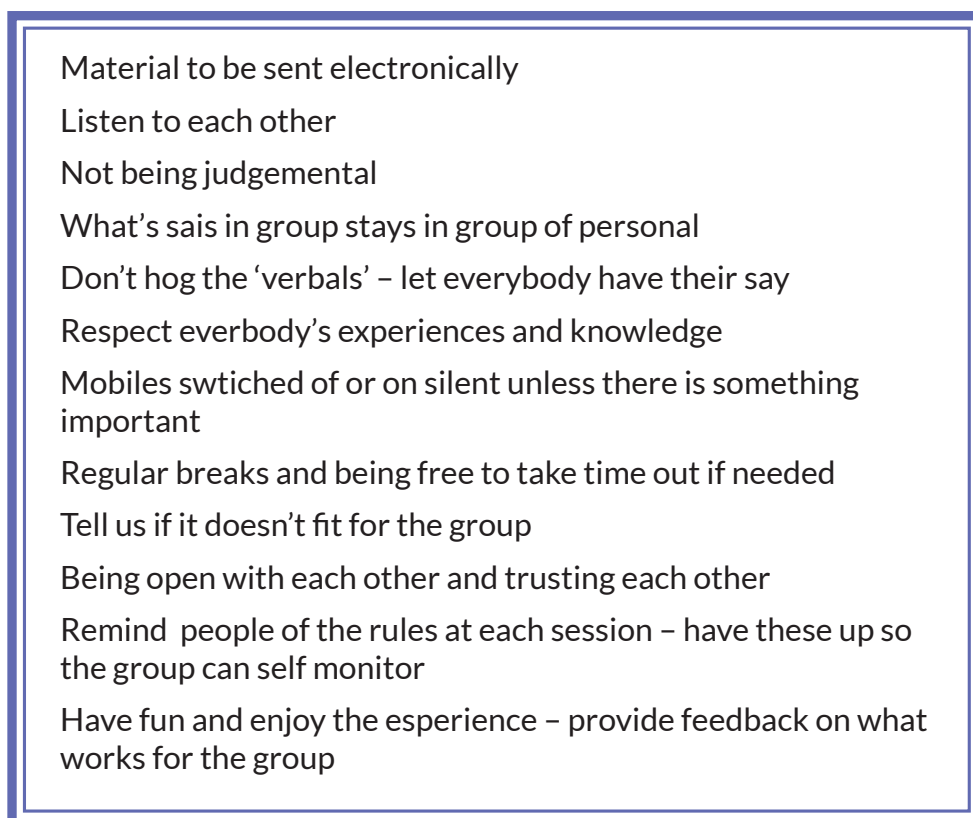
As the project progressed, and in response to expressions of interest from community researchers, opportunities to meet with other research teams were offered. Teams met together in Stirling to work on the project (particularly when developing the national survey). Opportunities were also provided to take part in conferences and networking events run by the funder – these provided additional opportunities to make connections with other academics and community groups.

It is also worth noting that successfully built relationships will also continue beyond the project and consideration must be given to how these will be maintained going forward. The university team in this project has ensured that there are opportunities to meet beyond the initial project to allow for further discussions around this project, and also on future joint ventures. Around half of the community researchers on this project continue to express a desire for partnership working. This allows the opportunity for greater involvement and dialogue before the start of projects, and also means that research proposals can be initiated from community researchers.

How did the key features of co-producing research find expression in your research?

Establishing ground rules

Community researchers completed a volunteer agreement, which set out the responsibilities of community and university researchers, and emphasised choice and flexibility in the process. Each research team also established their own ground rules at the first session and agreed to adhere to these. An example of one group's ground rules is shown in the following image.



Ongoing Dialogue

Dialogue prior to the start of the project was not possible as community researchers were recruited following funding being received. There was flexibility in the funded approach to enable modifications in the process retrospectively (see the section on 'Flexibility'). For example, the location and frequency of research team meetings was decided after consultation with interested volunteers. Ongoing dialogue was supported as each team met on eight occasions. In addition, and in response to the wishes of community researchers, two all-team meetings were scheduled. Dialogue was further maintained through email, phone or face-to-face communication.

Joint ownership of key decisions

There was discussion around all key decisions. The emphasis was on reaching consensus, with mutually workable approaches being explored in the face of competing perspectives. There was full and transparent discussion of options before an agreed approach was taken forward. For

example, in the designing focus group session, university researchers provided initial training material on focus groups and how they would normally undertake these. In thinking about the approach to be taken in this project, there was discussion about the frustrations previously felt by community researchers when taking part in focus groups in the past, for example, the fact that these often provided no opportunity to get to know others taking part. Consequently, it was agreed that the focus groups would start with an ice breaker that would be related to the topic but also help to introduce each participant to the others in the group. This meant that focus groups were longer than initially anticipated (sometimes as long as 120 minutes). The research teams also decided upon who the participants would be in the project and following such discussions a decision was made to increase the number of focus groups from seven to twelve.

A commitment to relationship building

Regular team meetings supported relationship building. This relationship building went beyond the team. The commitment to relationship building was central in the ethos of helping to empower local communities. Community researchers facilitated connections with local communities. University researchers facilitated communication with professional networks, and the project created direct links with Age Scotland and policy makers. All researchers had the opportunity to participate in conferences and gatherings such as the University of Stirling's Dementia and Aging Research Group annual event, and the Life Changes Trust networking events. In conducting the research, and recruiting participants, there was a commitment to establish links with local or national groups that would have an interest in the research. This involved providing presentations to local groups, such as local older people's forums and engaging with local groups in the communities of the researchers.

Opportunities for personal growth and development

Community researchers accessed training on conducting ethical research, and in some instances on using IT (i.e. digital cameras). The training provided was adapted to the needs of each research team and the skillset already within that team. The emphasis was on reciprocal training, whereby university researchers also had the opportunity to learn from the skills and expertise of community researchers, for example, in ensuring appropriate language and approaches to gathering data, such as appreciating local and cultural diversities and in thinking about how to create impact through research. All community researchers were provided with dementia awareness training with a view that community researchers would be better placed to support the engagement of people living with dementia in this project. People with personal experience of being a carer or relative of somebody living with dementia were able to share their experiences and knowledge here, further enhancing the formal training that was delivered.

Flexibility

We recognised at the outset that co-producing the project required greater flexibility which, in turn, could lead to greater costs. We had had the foresight to recognise that, as the final approach would be decided upon with community researchers, that each research team had a small "research support fund" that could be accessed and accommodate for additional expenses in conducting these. For example, in this project there was a request for additional focus groups, translation of research materials and additional team meetings. From the outset, funders were aware that the final direction of the project would be determined by the process and agreed after discussion with community researchers. We emphasised to funders how the model of co-production being used would mean that the voices of older people would not only be heard but

would shape and inform every step of the research. We set out clearly that there were a number of other reciprocal benefits that might be experienced by community researchers and provided case studies of the personal and community growth and development of those engaging with the project. We had expressed how this project was as much about empowerment and inclusion, as it was about producing outputs that heard the voices of older people.

Whilst there were overarching deadlines that had to be worked towards, for example phase one and two had to be completed by all teams before the survey was agreed, the design of the project also allowed flexibility in timescales. For example, the smaller research teams could shape research in their communities in phases one and two without impacting on the activities of other groups. This meant that, rather than be prescriptive of the timeframes for meetings, these were agreed locally with each team; the research activities could be scheduled around the commitments of researchers and other local events.

Valuing and evaluating the impact of co-producing research

The impact of co-production can be evaluated in different ways. At a wider level we evaluated our impact by making note of where the project had influenced policy development and how our project had influenced future co-production activities. At the individual level we asked people involved in the project what difference it had made to them and to others. Ro Pengelly, one of the community researchers, writes:

“Involvement in A Good Life with its holistic approach was so good, as there is an essential need for an integrated approach to at least housing, health and social care, especially while planners fail to ensure options for people who choose to downsize or relocate so to be closer to paid work, friends, family or amenities. The lack of choice leads to vulnerability, whereas choice would enable more people to remain safely home-based for longer, away from call on emergency public services, hospitalisation or residential care. I welcomed being involved in the project’s gathering and analysing of data, dissemination of findings, and connecting with local residents and community organisations, as that offered me the privilege of progressing the University of Stirling’s endeavours, by informing and strengthening links between policymakers and research community; and between teaching and actual trends in the labour market.”

We know from speaking with other co-researchers that being part of the project impacted on individuals in a number of different ways. Volunteering on the project gave people a perceived benefit to themselves (an uplifting feel good factor) and they enjoyed the stimulation of working with the wider team, knowing that something useful was being done, whilst meeting other people and learning new things. Some people reflected on how they had become a community of “co-researchers” and they thoroughly enjoyed working with other people and were able to keep their research, writing and editing skills honed! Everyone joining the project came with their own skillset and valuable knowledge but this project made some people feel they were further informed by the process and made them more aware of alternative perspectives and experiences. Co-researchers highlighted how being involved in co-production gave the opportunity “to keep the brain ticking” while being able to contribute to an area of research that they had to consider for themselves.

In the longer term, people felt that they had made a contribution not only through the findings but in helping to shape true partnership working by sharing their views about co-production. Throughout the project we regularly sought feedback on what was working (and what wasn’t) and this ongoing evaluation was essential in shaping the way the partnership evolved.

Continuous reflection

Each meeting with community researchers included an opportunity to reflect on the project. Community researchers were asked to express what worked well and what was less successful. This was encouraged from the outset of the project. University researchers explained that this was the first time they had run a project like this. They were candid that there may be room for improvement and were keen for any feedback to be shared. Where possible any concerns or areas for improvement were actioned immediately and ahead of the future gatherings/meetings of the teams.

Research training provided during meetings was modified and adapted in light of reflections. For example, the meeting on visual methods included some initial training on the ethics of undertaking such research. The first team that received this advised that parts of the training were disheartening and focused on what was not possible. Suggestions were made about reframing the training. This was taken on board and later teams were provided with training that covered the same points but also included time for team members to discuss creative solutions on how certain topics (e.g. enjoying time with grandchildren) might be captured visually whilst still adhering to the ethical approvals gained.

Key challenge: Overcoming power differentials

At the outset of the project university researchers naively felt that we could gather the perspectives of older people and widen our understandings through simply bringing together university researchers with 30 community researchers from a range of communities across Scotland. However, we soon realised the challenges that can emerge from traditional power relations in research and the impact that these have on the relationships between universities and communities. At the start of the project some community researchers felt that the direction should come from the university – it was often suggested that the focus should be about the project leading to what the university wanted. This meant at the start of the project there was a need to break down pre-existing beliefs and expectations relating to power relations within more traditional methods of research. Raising confidence in community researchers as being experts in the research process, being open and transparent in discussions, reiteration of the model of co-working and demonstrating through the practice of taking forward ideas, were all key in establishing a culture where the perspectives of both community and university researchers would freely and equally be brought to the table. Fostering this culture of equality takes time and it was somewhat fortunate that our transitional approach to sharing power enabled the gradual increased influence of the perspectives of community researchers over the direction of the research.

Key benefit: The power that co-production gives to the public and communities

Co-produced research plays a part in breaking down barriers. In this instance tackling some of the existing power divides that exist between universities and communities in the research process. This project also served to challenge stereotypes of ageing and neediness, particularly where people are living with longer term health conditions. By recognising and accepting the talents and skills of older people, it adopted a “can do” perspective and illustrated how older people can and do still make a contribution to their communities. In providing a new role for those taking part, it provided the opportunity to take control and be active in driving forward changing views of ageing, not only in terms of the findings produced, but also through the process itself. Through co-produced research, individuals and communities are able to have a more direct role and involvement in generating knowledge that will feed into policy and practice. This means that policy and practice is more reflective of the lived experience of different communities.

Five key learning points:

- Co-production on a larger scale, with multiple community researchers and across multiple sites is possible and has valuable results for teaching, research, practice, and for individuals through the inclusion of their thoughts and ideas.
- Small local research teams can support relationship building and ensure diversity of experiences, needs and wishes are captured.
- Flexibility is essential. Budgets need to have room for expenditure on approaches emerging during the project and principle investigators need to be willing to move from proposed project plans.
- Co-production is not a project but a process – relationships will continue to need support and impact will continue to exist beyond the funding period. This needs to be planned for.
- It is sometimes suggested that co-workers should receive fair financial reward for their involvement. This might be appropriate in some scenarios. However, there may be other instances where financial remuneration is not welcomed, may be problematic or where this can curtail equality of knowledge and freedom of expression. There is a need to be aware of both the benefits and pitfalls of financial remuneration of co-researcher time, and to acknowledge reciprocal benefits that extend beyond financial remuneration that could and should be embedded into the project design.

3

The National Institute for Health Research (NIHR) Child Prosthetics Research Project

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Organisations involved in the research:

NIHR Devices for Dignity (D4D) MedTech Co-operative (hosted by Sheffield Teaching Hospitals) lead, input from Lab4Living (Sheffield Hallam University). In addition, charities (including Limbpower and Steps), numerous NHS organisations, including Trusts from across the UK. Larger companies from industry, Blatchfords, Steeper and Opcare as well as the smaller small and medium-sized enterprises (SME's), such as Team UnLimbited and 3D Lifeprints, with a focus on prosthetics for children.

Summary of the research

Following the announcement in March 2016 of the government's investment of £1.5 million in child prosthetics, D4D were given the role of leading the NIHR Child Prosthetics Research Project (also known as 'Starworks'). The project aimed to 'incentivize the development of new breakthrough innovative prosthetic products for the NHS.' By increasing the focus on research, the project aimed to accelerate the translation of new inventions and developments in child prosthetics into everyday use.

A core emphasis of the project was to encourage an active lifestyle for children with prosthetics, with half of the £1.5 million being dedicated to the provision of activity limbs (i.e. running 'blades' or 'swim limbs') for children in England. As such, a key focus of the research was on developing activity limbs (rather than focus solely on one element such as 'running blades' as it could not be assumed that all children would require a particular prosthesis).

The approach taken was to establish a Child Prosthetics Research Collaboration, which brought together children and their families with key opinion leaders from healthcare, academia and industry. The project began with a 'needs assessment,' developing an understanding of current challenges within the system based on the views of these four key stakeholder groups. Data were collected using methods suited to each stakeholder group. For example, clinicians were engaged through online surveys (a quick task which could fit into their busy workloads) whilst young children were engaged through creative workshops and paper-based questionnaires that focussed on drawing and self-expression (see figure 1).

The findings from each workstream in the needs assessment were collated and used to inform the subsequent stages of the Starworks project. This included selecting four key ‘challenge themes’ to explore in a series of creative, collaborative Sandpit events across the country and the funding of 10 ‘Proof of Concept’ projects, described further below.



Figure 1: Workshop activities engaged children and parents in reflecting on their wider lives with prosthetics, identifying challenges and creatively generating ideas to address them. Metaphors such as ‘superheroes’ or ‘advice bubbles’ were useful in discussing prosthetic use in a fun and empowering way.

The children and families created a compelling case as to how and why a poor-fitting or cosmetically unappealing limb can really affect a child’s life at home, school and play. We chose to co-produce the Starworks project (rather than taking a traditional top-down approach) in order to engage and legitimise the unique expertise of the four key stakeholder groups (children and families, the NHS, academia and industry), as well as to ensure that the project was responsive to their specific needs and priorities from the beginning. As a result, we are now in the position to create a national network with these stakeholder groups to continue the Starworks legacy. This will enable children and families to remain at the centre of:

- Prioritising research focus
- Acting as an expert group within the network, offering opinion and advice on new prosthetic-based innovations
- Supporting bids for continued funding for research opportunities

Links to the research:

http://devicesfordignity.org.uk/starworks_cp/

How did the key principles find expression in your research?

From an early stage, it became clear that children and families rarely have the chance to share their lived experiences with healthcare practitioners, academics and industry experts together (as outlined in figure 2 below).

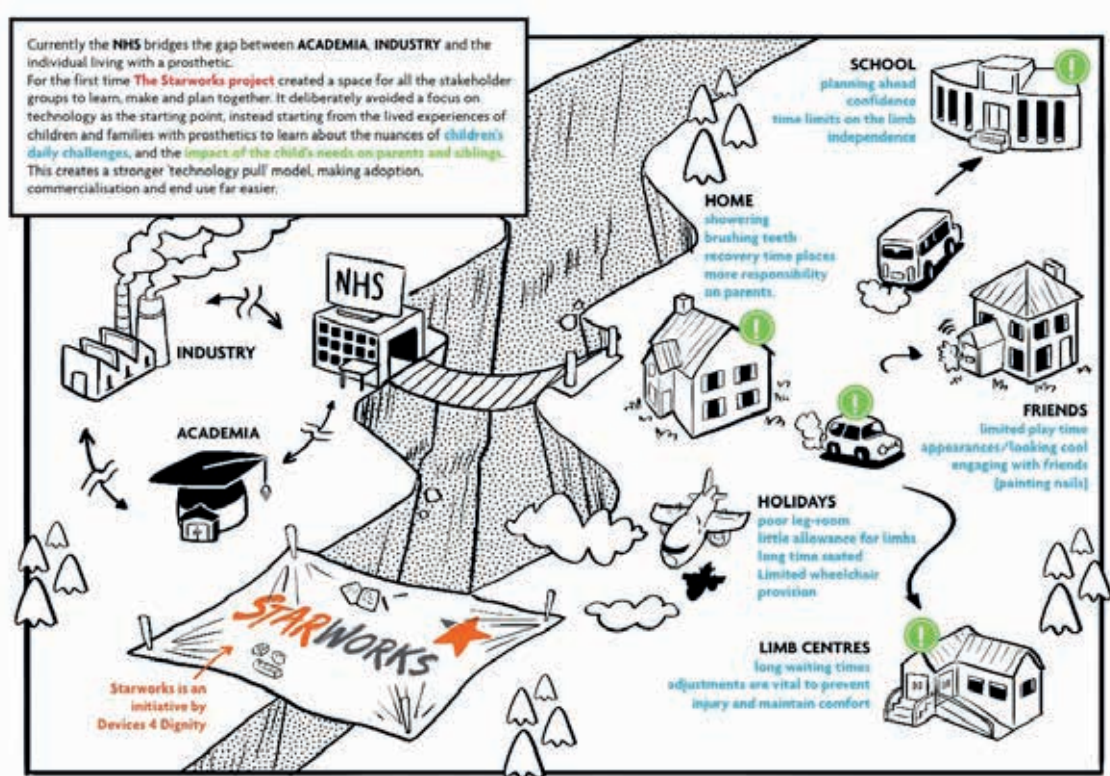


Figure 2: Positioning Starworks in the research landscape of children's prosthetics, as well as highlighting some key challenges faced by children and families.

As such, the principle of **including all perspectives and skills** was a key concern in this project. This was embodied in an initial multi-stakeholder needs assessment, which in turn informed the 'challenge areas' of four Sandpit workshop events across the country, as described above. The Sandpits (workshops with a focus on creative collaboration to explore and address key challenge areas) were open to participants from each of the stakeholder groups (to facilitate the **sharing of power** in the research) and involved:

- Problem definition – presentations from each stakeholder group, to understand the challenge area in their own words.
- Inspiration and ideation (the formation of ideas) – each workshop had a range of guest speakers and/or exhibitions of innovations related to the workshop's challenge area. This aimed to help participants think more widely about how that challenge could be addressed. This was followed by a range of creative activities to facilitate mutual learning (i.e. 'draw the person next to you in two minutes' which kick-started conversation between participants in a playful manner) and idea generation (i.e. beginning with a competition to create the wildest new product by combining random objects, before moving on to creating solutions to the challenge area) between diverse stakeholder groups. The workshop activities aimed to identify key issues and then focus on solutions to common problems faced by children with limb loss.

- Voting for ideas and developing the top five - inviting the whole group to vote on the best ideas generated, to decide which concepts to develop in the second half of the Sandpit, encouraged a sense of **respect and value for the knowledge of all those working together on the research**. The developed ideas were then pitched back to the rest of the group, so their comments, perspectives and skills could be included in further idea development.
- Establishing collaborations – in parallel to the Sandpit workshops, the Starworks project opened a call for applications to ‘proof of concept funding’ for innovations in child prosthetics (described in more detail below). As such, the Sandpit activities encouraged **building and maintaining relationships**, and provided tools to help mediate the nature of collaboration agreements (see figure 3). The tool in figure 3 enabled people to indicate which of the pitched projects they were interested in participating in, and what level of involvement they felt comfortable with.

The form is divided into two main sections. The left section, titled "I would like to be involved in these projects...", features a vertical column of eight orange stars. Each star is positioned above a horizontal dotted line for text entry. The right section, titled "I can be contacted by...", contains three rows of checkboxes and icons: a phone icon for "Phone:", an envelope icon for "Email:", and two person icons for "In person:". Below the "In person:" checkbox is a sub-section labeled "For..." with three options: "Participation" (pencil icon), "Advice" (question mark icon), and "Updates" (speech bubble icon). To the right of these options is a vertical column of dotted lines labeled "Notes".

Figure 3: A tool for attendees to indicate which of the pitched projects they were interested in participating in, and what level of involvement they felt comfortable with.

The creative activities used in the workshop, particularly during the ideation stages, also encompassed the key feature of **opportunities for personal growth and development**, as many participants previously felt that they weren't 'creative' or accustomed to developing ideas with participants from different disciplines. Whilst the paediatric focus of this research provided a clear rationale for the creative activities in the Sandpit events, we have found them equally effective in groups of adults also. Giving groups of experts (whatever their speciality) permission to explore 'blue sky' ideas can lead to meaningful innovation in the longer term, and creating a sense of 'playfulness' in such activities can build trust and strong working relationships between diverse stakeholder groups.

We also made sure that we were **including all perspectives and skills** by:

- *Embracing a diversity of perspectives* – small details such as developing table plans with a mix of disciplines supported participants in making new connections and incorporating different experiences in their ideation.
- *Recognising and addressing underrepresentation* – the initial needs assessment highlighted the different needs of upper and lower limb prosthesis users, with the former often receiving less research attention. As such, two different Sandpit events were arranged to explore ‘personalisation and adaptation’ from these two perspectives.
- *Considering the practical needs of inclusivity* - the inclusion of child and family perspectives was supported by the deliberate choice of ‘neutral’ venues in which they would feel comfortable (for example, a museum) rather than academic or clinical settings. We also chose venues that could offer additional ‘fun’ activities alongside the Sandpit event, so parents would not need to arrange childcare for siblings. This included the ‘We the Curious’ centre in Bristol, who offered a private planetarium show for the child participants, and the ICE Sheffield Ice Rink, Sheffield, who offered a curling session after the workshop. In addition, two of the events were held on Saturdays so children could attend without missing essential time in school.
- *Considering the information needs of inclusivity* - the Sandpit events were well-promoted through a range of medias (including social media, website presence and promotion through related charities) in appropriate, understandable language. Articles and event information text were proof read by colleagues outside of the core team to minimise the use of jargon or shorthand that the team had become accustomed to.

How did the key features involved in co-producing research find expression in your research?

Joint ownership of key decisions and a sense of **flexibility** were embodied throughout the project. Whilst (as with any project of this kind) a plan was created to guide the project structure, the content and focus of the research was responsive to the insights that emerged from multiple stakeholder groups. On a macro level, findings from the initial multi-stakeholder needs assessment informed the choice of challenge areas to focus on in subsequent Sandpit events. For example, data from the initial needs assessment highlighted that whilst many clinicians may talk about the aesthetics of prostheses in terms of encouraging uptake, parents and children discussed how the look and feel of the prosthetic can impact on a child's identity or emotional wellbeing in more detail. In addition, it became apparent that children may wish to customise their prosthetic in terms of its function as well as how it looks. As such, two workshops were dedicated to 'personalisation and adaptation' (concentrating on the distinct needs of upper- and lower-limb prosthesis users separately).

The structure of these Sandpits was also adapted over time based on feedback data from attendees. This included varying the time dedicated to breaks (to optimise the flow of the day whilst also allowing enough time for networking) and also adapting the bespoke tools generated by design researchers to support the individual activities (see figure 4 overleaf).

Idea Generation Sheet: Draw & annotate below

What is the biggest benefit?
What is the biggest risk?

Who is it for?
Is it child-friendly?

Do different people use it?

When is it used?
How is it used?

How long does it last?
What happens if it breaks?

What is it made of?
How much is it?
How is it made?

Will it help activities of daily living?

Idea Generation Sheet: Draw & annotate below

Idea Name:	
Idea Theme:	
Biggest benefit:	
Who uses it?	
Child	Family
Healthcare professional	Other?
Which area does it help?	
Activities of Daily Living	Play
Hospital Visits	Other?
Is the idea...	
Child-specific	Generalisable

Figure 4: Idea Generation Sheets

Idea Generation Sheets were created to support ideation activities in the Sandpit events. These sheets aimed to capture quick, rough ideas (where participants were encouraged to aim for quantity, rather than quality), before voting on their favourite ideas from the whole group. After trialling the first version of the 'Idea Generation Sheet' (shown top - figure 4), it was found that

participants often voted for ideas that were easy to understand at a glance, with a clear idea name. As such, the Idea Generation Sheet was developed (shown bottom – figure 4) to encourage participants in future workshops to include such information.

On a micro level, attendees at each event were empowered to choose which concepts to develop together through a voting process. All of the Idea Generation Sheets completed in a workshop were displayed on a wall over the lunch period, when participants were given five voting strips (stored in their name badges) to distribute as they wished (either all on their favourite idea, or spread across a few). To avoid bias, votes were posted in envelopes next to each idea, then tallied by facilitators, with the top five scoring ideas taken forward to be developed in the afternoon (see figure 5).



Figure 5: An example of the voting process at our Sandpit in Media City, Salford.

Ongoing dialogue and a **commitment to relationship building** is well evidenced in the activities following the ‘sandpit’ workshop events described above. As a part of the Starworks project, teams of stakeholders (children and families, NHS, academia and industry) were invited to apply for up to £50,000 in funding to solve some of the needs identified to create new Proof of Concept innovations. As part of the application process we suggested that each individual project have someone on the team from each stakeholder group. Eighty percent of the funded projects are working with either a single family or a group of families on their projects. They are seen as being at the centre of the design process, and as such the children are learning about multi-stakeholder approaches to innovation, research application and having lots of fun in working within these projects. D4D have supported applicants to the Proof of Concept funding in writing their bids and in setting up collaboration agreements, providing **opportunities for personal growth and development** that may support their continued involvement in research (particularly those with little previous experience in this area).

In such a complex research context, **valuing and evaluating the impact of co-producing research** can be difficult and multifaceted. As such, we will discuss this under the headings of *Valuing the Outcomes*, *Valuing the Process*, *Addressing a Gap* and *Responding to Real Needs*.

Valuing the Outcomes

The effectiveness of this work is evidenced in the volume of needs identified and number of ideas generated – 234 in total. After an initial analysis of these ideas, they have been mapped onto approximately 59 problem areas or themes; 15 of which did not emerge from an initial ‘traditional’ needs assessment and largely focus on the lived experience of children using a prosthetic (see figure 6) rather than clinical aspects.

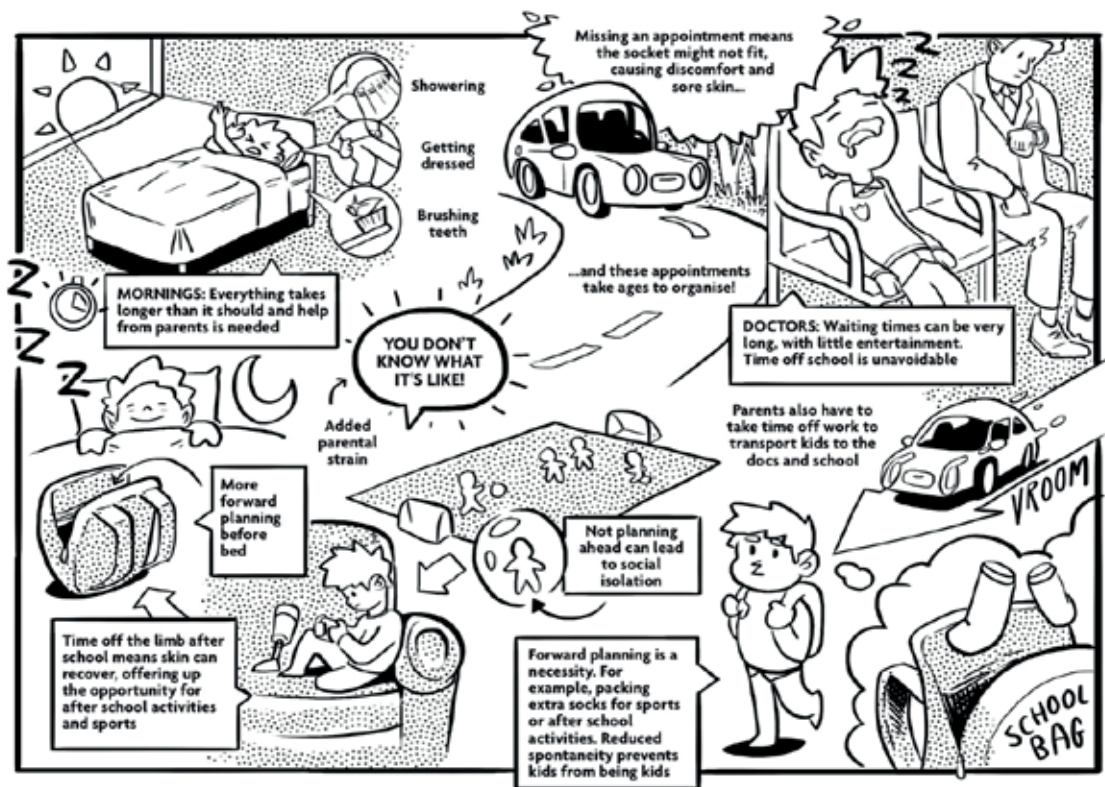


Figure 6: A ‘day in the life’ of a child using a prosthetic.

Valuing the Process

As well as evaluating the outcomes of projects such as this, it is important to also evaluate the process – especially in complex contexts such as healthcare. In the spirit of co-production, we invited participants to share in the evaluation of the Sandpit events themselves, and responded to their comments in the design of subsequent workshops (as outlined above). Our feedback forms also suggested that the opportunity to creatively and collaboratively explore the challenge areas with people from other sectors, including families, was one of the biggest benefits of the Starworks project from the participants’ perspectives. It is all too common, especially in healthcare, for experts to work in silos and not have the opportunity to learn from different, but related, perspectives. Whilst there can be many organisational or practical barriers (i.e. ethics applications or lack of resource) to including families in particular in such research, we found that the facilitation of conversations that quickly cut to the real issues, and applied the expertise of multiple stakeholder groups in addressing them, justifies such efforts.

Addressing a Gap

Our initial research highlighted that dedicated research within child prosthetics is very limited. 100 projects in the field of prosthetics (including implantable and external prosthesis, such as eyes and ears) were identified, totalling £44million of research funding. Only 10% of this funding was relevant to limb prosthetics and none specifically targeting children or young limb prosthesis users.

Co-producing the first research project of its kind in this area has resulted in a series of immediate outputs that are truly responsive to the lived experiences of children and families, and also build strong foundations (in terms of capacity and motivation) for continued collaboration.

Responding to Real Needs

Our research has catalysed the drive from government and across stakeholders to focus on research in this area. Our children and families created a compelling case as to how and why a poor-fitting or cosmetically unappealing limb can really effect a child's life at home, school and at play. Rather than continuing to appropriate innovations in adult prosthetics, we have seeded the attitude that children have unique needs and specific expertise to offer in the design and development of context-appropriate solutions.

Five key learning points:

- The use of creative methods can enable diverse stakeholder groups to communicate meaningfully across disciplines and hierarchies.
- Exposure to co-production principles and methods can have continued impact on those involved. For example, several of the teams awarded Proof of Concept funding applied these principles in their own projects after experiencing them in the sandpit events.
- There are many facets to enhancing the 'inclusivity' of a co-production project. For example, in this project it was particularly important to:
 - Choose venues that were easily accessible by public transport, with space that was conducive to creative, collaborative activities, and was easy for children with prosthetic limbs, running blades or wheelchairs to navigate.
 - Choose venues that had additional activities to entertain siblings.
 - Schedule half of the Sandpit events on weekends to minimise impact on schooling.
 - Ensure information about the project was in language that was understandable to those without prior experience in research.
- The principles of co-production remain relevant into later stages of research projects, including evaluation and dissemination.
- Whilst Intellectual Property issues are important, we have found that most participants are driven by a desire to create positive change, and are resourceful in navigating these potential obstacles to collaboration.

Useful references for co-producing research:

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INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

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