1001.2. Starworks: Politics, Power and Expertise in co-producing a research, patient, practice and industry partnership for child prosthetics

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ABSTRACT   *Significant advances have been made in the field of adult prosthetic limbs. Conversely, paediatric limbs suffer from a 'market failure' situation; market forces are inadequate to stimulate product innovation. Children are left with inadequate limb provision at best aiming to minimize pain and discomfort rather than enable independence and quality of life.*

In 2017, the UK Exchequer announced £1.5M one-off investment in child prosthetics, as a result of lobbying by charities and a small number of parents of children with lower limb loss. Half this investment was dedicated to the provision of 'activity limbs' (eg. running blades) for children, and half dedicated to research and innovation over a period of two years. The authors took a lead in the latter, with the aim to re-structure the market forces, catalysing innovation for more appropriate paediatric prosthetics.

NIHR Devices for Dignity MedTech Co-operative (D4D), supported by Lab4Living, established a network of key stakeholders based on principles of co-production (Greenhalgh et al. 2016). Details of the process, outputs and impact can be found elsewhere (Mills et al. 2019). This paper focuses on the politics, power and distinctive contributions defined by differing expertise, by which this collaboration was established, operated and sustained. We discuss the co-design methods that helped to achieve this and draw on evidence from the stakeholders and project outputs to demonstrate success of these methods.

We conclude by suggesting meaningful co-production isn't necessarily about including everyone in all decisions, provide some tips for managing political relationships and power differences, and highlight the importance of valuing stakeholders for their (unique) expertise.

Keywords: Co-production, prosthetics, paediatric, innovation.

Introduction

There are an estimated 60000 people in the UK with an amputation or congenital limb deficiency attending specialist rehabilitation services across 35 centres. NHS England spends about £60 million/year on these services (NHS England. 2015). Of these, only a small fraction are children; 2000 as a best estimate (Sky News. 2020). Numbers are uncertain due to lack of a central database of UK amputees and prosthetics users.

By 2016/17, a succession of events (2012 Paralympics, 2014 inargual Invictus Games, on-going Afgan war and increasing prevalence of Type 2 Diabetes) had increased population awarensss of prosthetic limbs and limb difference. Prosthetic limbs had changed from plastic legs attempting to look 'normal' to robotic limbs with complex articulating joints, a wider range of functionality supporting a wider range of activities; both daily activities, sporting or lifestyle adventure activities.

In comparison, prosthetic limb provision for children was limited. The numbers of children requiring prosthetic limbs (compared to adults) is very small. Rapid changes in body size and shape mean limb redundancy and turnover is higher; related to growth not just wear and tear. This ruled out costly limb options on NHS procurement, focusing provision more narrowly to functional requirements. For very young children, this is often simply biomechanical stability, ensuring the weight and presence of limbs support the balanced development and alignment of the whole body. Often a practical constraint of size and space limitations between the floor and residual limb only allows a single rigid structure with zero degrees of freedom.

The circumstances described above constructed a market situation stifling innovation and development in children's prosthetics. The extent of technological advancement in prostheses for children was making cosmetic 'sleeves' or smaller adult versions which work for limited situations. However, children should not simply be viewed as smaller adults; their lives and needs are very different. Moreover, the cost of smaller adult prostheses was prohibitively expensive due to limited production numbers at the smaller sizes.

The Exchequer's announcement in March 2017, resulted from sustained lobbying by a small group of parents of children with lower limb prostheses, supported by a few charities (eg Limbpower) for children with limb difference, and was originally dedicated to the provision of activity limbs. Whilst this funding would provide some children with a greater choice of prostheses, the numbers of children who could benefit and duration of availability was limited. To have a sustainable affect, something structural needed to change. A case was made for a more strategic view, diverting half the funding to research that restructured the market so limb provision and innovation of those limbs could be more sustainable.

The authors took a lead in this research, but knew that they didn't have all the answers and would need to adopt a co-production model. However, many of the stakeholders vital to the work were those lobbying for and supporting the funding of activity limbs, and did not necessarily have a 'stake' in the more abstract benefits of research (system changes of benefit to the next generation).

Background

Co-production (or co-design) literature is diverse yet as far as we could determine there is nothing refering to co-production to tackle 'market failure'. There is broad agreement across this literature about key success principles which include:

> '…taking a systems perspective (assuming emergence, local adaption and nonlinearity), framing the endeavor as a creative enterprise with human experience at its core and an emphasis on process (framing of the program, the nature of relationships, governance and facilitation)….'

> (Greenhalgh et al. 2016)

Various authors (Bevir et al. 2019; Oliver et al. 2019; Flinders et al. 2016) outline risks associated with co-production; namely identifying appropriate stakeholders, competing interests and motivations, time, ethical complexity, emotional demands, inherent instability, vulnerability to external shocks, subject to competing demands and challenges to many disciplinary norms. These authors emphasised the importance of practical processes, methods of facilitation and the need to continuously (re)clarify outcomes or expectations.

Nicholas et al. (2019) developed a Critical Systems Heuristics' framework for co-productive initiatives, posing queries about Motivation, Power, Expertise or Knowledge and Legitimacy. Farr (2018) suggests using constant critical reflective practice and dialogue to 'check' levels of equity or power balances.

The authors' previous co-production experiences reflected these issues (Langley et al. 2019; Sheard et al. 2019; Goodwin et al. 2017). Of interest to this case, the authors had support of funders and Department of Health, but needed to 'win over' key opinion leaders from parents and clinicians; those who had campaigned to secure the funding. Some may have preferred all the funding to have facilitated activity limb provision, and/or some felt a co-production process would not identify new issues or solutions.

This account of Starworks, is followed by a discussion drawing on the above literature, exploring our methods of co-design facilitation in terms of levelling power and the concept of expertise, suggesting stakeholders do not have to be included or involved in all stages and all decisions for it to be defined as co-production. It is more important to recognise genuine expertise stakeholders bring and collaborate with them at relevant points/activities in the process. Applied in this way, we suggest change is more likely to happen; in our case change for the sector (addressing market failure) and for CYP with prosthetics limbs.

Approach

Phase One: establishing the network

It is to be recognised that four key stakeholder groups have been central throughout the Starworks project; clinicians, academics, industry experts, and (most importantly) children and families. The Starworks team engaged with relevant clinical, academic (eg. health research, prosthetics

technologists, materials engineers) and industry networks to attract the best talent, ideas and collaborations that have expertise in child prosthetics. For this, the Starworks team undertook primary research to gather knowledge on key personnel, groups, academic and industry opinion leaders. This included face to face meetings and interviews to gain opinions and understanding of issues around child prosthetics from the range of stakeholders' perspectives. Alongside this, we worked with charities and created open social media channels to engage with children and families. This early engagement was successful in gaining trust and understanding from the children and families.

Given the diversity of participants involved, several issues were identified as being problematic in encouraging collaboration. These included giving equal voice to all participants, potentially conflicting perspectives, eliciting issues occurring in everyday life, and engaging children in a fun and relevant way. These issues were anticipated in the methods used in Phase Two (engaging workstreams separately in context-specific ways) and in Phase Three (in the considered workshop structure).

Phase Two: multi-stakeholder needs assessment

Consideration of the multiple perspectives of children's prosthesis development and provision has been at the heart of Starworks from inception. The aim of this was to understand the current status of development and provision, identify opportunities for further research (summarised in ~~the~~ table 1~~below~~), to in turn inform Phase Three ~~of the project~~.

Table 1. table of stakeholder groups, methods of needs assessment data collection and response rates

Workstream	Lead Institution for delivery	Methods	How many people were contacted?	Response rate
Children and Families	NIHR Devices for Dignity HTC & Sheffield Hallam University	Surveys	Approx. 1000 surveys were sent to 500 families (2 per family) at 5 sites across the UK	10 Children, 4 Young Adults and 16 Parents
		Phone calls, individual contact with stakeholders and hospital visits.	2 Children, 6 Parents and 16 Clinical Professionals	
		Workshop activities engaged children and parents in reflecting on their wider lives with prosthetics, identifying challenges and creatively generating ideas to address them.	18 Families	
Clinicians	The NIHR Health Technology Cooperative in Brain Injury in conjunction with Dr. Stephen Kirker	Clinical Audit to establish demand for prosthetics services and activity limbs	34 limb centres	11 limb centres
		Surveys to establish unmet needs within the prosthetic service, managers and medical rehabilitation specialists and a smaller survey circulated to the rehabilitation engineering community and allied health professionals	Approx. 4600 healthcare professionals	67 full and partial responses
Academia	NIHR Trauma Management HTC, Birmingham UK	Review of publicly-funded research projects in the UK, using database searches of funding bodies.	Databases included Research Council UK Gateway, The Wellcome Trust, i4i and SBRI.	94 projects deemed in scope
Industry	TRUSTECH	Desk-based research and Social Media		
		Online survey	Contacted 10 key companies, publicised through Trustech Twitter account (1,392 followers), LinkedIn account (69 followers) and website.	38 full and partial responses
		Telephone interviews with key players		13 interviews
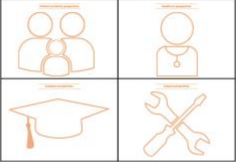
Phase three: sandpit events

The core co-production effort in this work focused on bringing representatives of these four stakeholder groups together through four sandpit events exploring challenge areas emerging from phase two. These challenge areas, nominated by the authors from information gathered through Phase two, were '*Socket Interface', 'Upper/Lower Limb Personalisation and Adaption' and 'Service Journeys'*. Although based on input from all stakeholders, these areas were chosen by the authors to identify key, recurring issues, whilst remaining broad enough for interpretation by Sandpit delegates.

To facilitate the participation of as many different delegates as possible, the Sandpits were hosted across the country. They were attended by 90 delegates, including:

- 6 young people who use a prosthesis aged from 2 to 15 years old

- 9 family members of young people who use a prosthesis

- 18 delegates from healthcare

- 30 delegates from academia

- 13 delegates from industry

The 72 professional delegates (comprising of 61 individuals) represented 33 institutions. The structure, rationale, content and outputs of the workshops are illustrated in figure 1.

Activity	Tool	Description	Tool in use	Outputs over four workshops
Problem Definition		Discuss the workshop theme from the perspectives of children, families, clinicians, academics & industry experts.		Approx. 15 new chalenge areas elicited
Inspiration		Showcase a range of inspirational materials, projects and research related to child prostheses, as well as analagous materials to inspire creative thinking.		Participants viewed 4 exhibitions, plus talks and/or demonstrations from 7 professional groups and 2 families
Ideation		To collaboratively generate as many ideas as possible in multi-displinary teams, supported by a design facilitator. Wild ideas were encouraged from every attendee, then the whole group voted for their top 5 ideas over lunch.		234 ideas mapped onto 59 problem areas
Develop & Pitch		Once participants self-select which of the winning ideas they want to work on, the teams develop the idea further (also highlighting what they don't know at this point). The concept is condensed into an 'elevator pitch' and presented to the group.		18 pitched ideas, 23 applications to proof of concept funding

As shown above, the Sandpits elicited a range of new challenge domains, the majority relating to children living their lives rather than clinical concerns.

Phase four: proof-of-concept funding

A national call for applications for 'Proof of Concept' funding to address key challenges within Child Prosthetics technology and provision was launched in September 2017. Applicants were required to adopt a co-design, multi-stakeholder collaboration, which was evidenced within the 23, high-quality applications. These were subject to external peer review. Those defined as fundable were developed further between the Starworks and project teams to refine methods or partnership agreements. Ten projects were funded and monitoring and support appointed for each. IP rights were assigned to the project partners in each case.

Phase five: maintaining and growing the network

This phase focused on increasing the individual and organisational engagement with Starworks from all stakeholder groups. An 'expert network' has been established, including 3 charities representing children and families, 12 clinical organisations, 7 industrial organisations and 15 academic organisations. A 'Starworks Ambassador' network has been joined by over 25 children with limb difference and siblings to date.

Additional funding (£427,000. NIHR.) was secured to further explore other areas of research identified by the group, such as developing outcome measures meaningful to children and families as well as clinicians, academics and industry.

Limitations

No detailed, formal, summative evaluation of Starworks has been undertaken to date. Rather, we have used less formal, formative approaches to ongoing evaluation – using feedback from each event or from PoC projects to continually adapt our approaches to the needs of the network. We will offer some of these in the discussion section.

Discussion

There is smuch to discuss about the Starworks project. In this paper we focus on the challenges in establishing the network, the importance of knowing the stakeholders (and letting them know you), methods of facilitation and the central notion of expertise – all of which address the overarching issue of power between stakeholders.

The early resource invested in finding out 'who' the key opinion leaders were across the four stakeholder areas were significant. Publicly available channels of publications, websites and social media were explored and cross referenced. Private channels using email, telephone calls, meetings, word-of-mouth etc were used to further identify individuals. This work took on several phases;

1) identifying key opinion leaders
2) pitching a case and inviting or requesting them to contribute to the initiative
3) determining roles in terms of a Project Reference Group (PRG) or active project participation

4) writing the proposal with them and using this proposal as a tool to determine and clarify motivations, expectations and outcomes for each person/organisation involved

This work took several months before funding was secured but was foundational. Point 3 is a hugely political judgement. Some are only able to, or only want to, contribute in specific roles and these wishes must be respected. Others can greatly influence the progression (positively or negatively) in specific roles. Trying to create a balance of critical reflection in the PRG and practical action in the project team is key and some delicate framing of role is sometimes required. The NIHR mandated some funding was spent with the other seven Healthcare Technology Co-operatives, meaning their expertise was sought in areas that added value to the project.

This 'groundwork' came to fruition in the sandpit events. The pitch and tone of the subject matter was suitably 'lay' to enable all stakeholders to understand and engage. The content resonated with all stakeholders due to the background needs assessment. Visual methods were used to represent needs in these areas and highlight how they may differ according to stakeholders' distinctive perspectives, with time to develop these understandings at the events themselves (see the 'problem definition' and 'inspiration' sections of fig. 1). This had a powerful impact on all stakeholders present as an introductory frame for the sandpits, immediately creating an open mindset. It helped to build trust with families, who could see they were being 'listened to' – their voices and needs could not be ignored as their input became a physical presence in the room.

A crucial aspect of our approach was focusing on, and presenting the 'expertise' of each stakeholder. Groups of stakeholders had distinct, explicit and tacit knowledge – our design-based methods helped participants to reflect, share and learn from each other towards mutual understanding and shared problem-solving (see 'Ideation' and 'Develop' fig. 1). The vast number of new unmet needs and ideas identified through these collaborative sandpits is testament to the value of these methods.

The approaches we applied in the sandpits influenced the proof-of-concept projects, where we witnessed and guided academic partners to work collaboratively with other stakeholders. This suggests a longer-term, 'ripple' effect of creating large-scale co-production events such as the sandpits.

The greater legacy of the methods we adopted is in the decision to 'spin out' the network from NIHR funding into a collaborative Social Enterprise founded on representation of the four stakeholder groups. The equity between the stakeholder groups is being embedded as a core value in the draft Social Enterprise structure and governance. The work is ongoing and we look forward to continuing the collaboration through this structure.

Conclusions

Our experiences with Starworks have shown the importance of investing in getting to know people and building relations with organisations and individuals before setting up a co-production initiative. We cannot always choose our project partners, and some are easier to work with than others. Finding the right roles for people and organisations in crucial. The PRG acted as a point of critical reflection, voicing concerns, objections and suggestions. Our approach to these wasn't simply to acquiesce, and whilst we will never adopt a 'we know it all' attitude, we do have some faith in our

expertise in co-production. Experience has taught us to listen to all comments, to adapt our approach to some of the issues raised (often relating to content), and to ask for trust in our approach with others (often relating to process). This is a difficult line to take in terms of keeping ourselves 'honest' and constantly learning, improving and evolving our approach. However, using this frame of expertise helps us to justify these responses.

This frame of valuing 'expertise' is one we carry through our approach to every stakeholder, not just ourselves. People should be involved because of the expertise, knowledge and evidence they bring. Our approaches seek to draw out of stakeholders and participants what others don't know, and enable them to share these in ways that others can comprehend. The shared understanding is crucial but limited; some of that expert knowledge from one stakeholder can be assimilated by others, yet our approach also seeks to embed an appreciation that there is more expert knowledge (i.e. tacit knowledge) that is embodied by the stakeholder, affirming the need for on-going collaboration.

The methodological approach used in delivering this Starworks project, pending formal evaluation, proved successful. This does not depend on involving all relevant stakeholders in all decisions (for example, the choice of themes for the Sandpits was informed by all stakeholders, but ultimately decided by the authors). Aiming for constant consensus, we believe, is a fragile, reductive gesture at involvement that masks a lack of appreciation and understanding about *why* it is important to involve non-researchers in these co-produced research endeavours. Co-production in health contexts is complex, and meaningful involvement can be supported by design-led facilitation that supports multiple, often conflicting perspectives in a productive, respectful way. Such facilitation requires the acknowledgement of design facilitators' expertise in the *process*, equally to the acknowledgement of stakeholders' expertise in the *content*. To date this research has delivered, The national Starworks network, National database of children with prosthetic limbs and ten proof-of-concept innovation projects.

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