

ARC WM CO-PRODUCTION CASE STUDY

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ARC WM Theme	Research Methodology and Informatics
Project Name	MEMVIE: Mathematical and Economic Modelling for Vaccine and Immunisation Evaluation
Case Study Details	This case study describes the contribution of public contributors to mathematical and economic modelling for vaccine and immunisation evaluation.
Further information	https://warwick.ac.uk/fac/cross_fac/wider/activities/human_infections/memvie/

WHAT DOES THIS CASE STUDY SHOWCASE?

The Mathematical and Economic Modelling for Vaccination and Immunisation Evaluation (MEMVIE) programme aimed to explore, capture and support the potential contribution of the public to mathematical and economic modelling in order to identify the values that underpin public involvement (PI) in modelling. The project team co-produced a framework that identifies the nature and type of public involvement in modelling and supports its implementation.

WHAT IS THE PROJECT ABOUT?

There are areas where public involvement is much less common, including complex areas such as mathematical and economic modelling.

A definition of a mathematical model is a “mathematical framework representing variables and their interrelationships to describe observed phenomena or predict future events”. The epidemiological component captures the health-related outcomes. The health economic components of the model capture the costs and, ultimately, the cost effectiveness.

Modelling provides decision-makers with the best available evidence to reach a decision. However, involving patients and the public in all stages of health economic analysis could enhance models, improve confidence in and ultimately accelerate decision-making. Involving the public in modelling could also play a pivotal role in highlighting key areas for further research in modelling methods.

WHAT IS YOUR APPROACH TO CO-PRODUCTION?

We drew on the concept of co-production, which we acknowledge is a rare approach in modelling, noting the study started before the current NIHR definition, although we drew on this in latter stages of the study (Hickey, et al., 2018). The notion of co-production is founded on a number of elements or principles that are relevant in research. In identifying these, Heaton, Day & Britten (2015) use the term ‘users’ to refer to the service context. For consistency, we use public contributors.

First, in the process of co-production, public contributors are regarded as active agents and not merely passive subjects or recipients of services (or research). Second, there is greater than usual equality in the relations between public contributors and professionals, with services becoming more people driven, with their knowledge and experience being valued on a par with that of professionals. Third, public contributors and professionals recognise that they can achieve more by working together than they can apart; both also find their relationship to be reciprocal and mutually beneficial. Fourth, public contributors’ increased participation transforms the ways in which public services (or research) are designed and delivered, developing capacity for public contributors’ present and emerging needs to be met. Fifth, the participation of public contributors in the co-production of services (or research) is encouraged and facilitated by networks and organisations that support their involvement.

The use of the concept of a deliberative knowledge space and think-aloud techniques provided an open, non-prescriptive dialogue that enabled ideas and thoughts to emerge. The public contributors were able to challenge the data, the basis for the collection of data and the interpretation of that data, thinking outside of the box in a safe space where modellers could rework their thinking. The meetings enabled thematic development over time as the Reference Group contributors worked with the academic contributors on continuous iterations of the emerging framework. We held 21 MEMVIE meetings over 5 years, each lasting between 2–3 hours, with email contact in-between with the group commenting on documents.

HOW DO THE PRINCIPLES OF CO-PRODUCTION FIND EXPRESSION IN THIS PROJECT?

Sharing of power – Power was shared in how we conducted the discussions in the deliberative knowledge space. Sophie Stansizewska acted as a facilitator of the group but did not direct discussion. The public contributors and the research team made joint decisions about what should be included in the framework to guide public involvement modelling. Public contributors were able to identify any relevant points of discussion they felt were important to highlight. As we move forward in our next study, we will explore more specifically where power sharing can work in the MEMVIE model.

Including all perspectives and skills – The advantage of a deliberative knowledge space is that it welcomes and values all forms of contribution and knowledge. This was particularly important in this project because we were developing new knowledge about the potential for public contribution in modelling which does not exist in the literature. Our public contributors brought a range of skills and knowledge from their rich and diverse backgrounds. As Williams and Popay (2001) say of the public “they are themselves bearers of considerable lay knowledge of their own life worlds and through their own ‘stocks of knowledge at hand’, were skilled interpreters and translators of the ‘external’ evidence provided by professional experts in dialogue with whom they could share in the decision making about what was to be done”.

Respecting and valuing the knowledge of all those working together on the research – Our approach in the MEMVIE study was to explicitly value the knowledge of all those working together. The research team brought important content and methods knowledge and the public contributors brought important experiential knowledge, in addition to clear and complimentary values that underpin their motivation to contribute and demonstrate the potential impacts that public involvement can make on a study – for example enhancing the transparency of a model. Our approach was underpinned by our approach to knowledge generation that values patient-based evidence alongside clinical and economic forms of evidence. In addition, we recognise the vital role that public contributors have in shaping patient-based evidence in addition to the clinical and economic forms of evidence (Stansizewska & Werko, 2017).

Reciprocity – We expressed reciprocity by ensuring the dialogue between the research team and the public contributors covered areas of importance to public members. We looked for opportunities where the Public Reference Group wanted to make other contributions. For example, they were keen to respond to the National Survey of Sexual Attitudes and Lifestyles (NATSAL) consultation on the sexual behaviour survey, which has informed one model. Another example was the response we wrote to the National Institute for Health and Care Excellence (NICE) consultation on methods in health technology assessment. The Public Reference Group thought both these endeavours very valuable although they sat outside the immediate focus of the study.

Building and maintaining relationships – A key element within MEMVIE was the time we spent building relationships building on the key elements of the [RAPPORT study](#), which identified the importance of an appropriate arena for relationship building, time and a sense of reciprocity (Wilson, et al., 2015). We ensured public contributors felt comfortable to contribute, that people got to know each other and that the environment in which we met was comfortable. We did move venue to ensure our public contributors avoided problems with parking to a much more pleasant venue with high quality drinks and snacks.

HOW DO THE FEATURES OF CO-PRODUCTION FIND EXPRESSION IN THIS PROJECT?

Establishing ground rules – We drew on the [NIHR UK Involvement Standard](#) for ‘Working Together’, which includes elements such as respectful listening. We tried to ensure everyone had an opportunity to contribute.

Respectful challenge was always encouraged. As facilitator, Sophie Staniszewska focused on ensuring everyone felt safe in the deliberative knowledge space.

Ongoing dialogue – Over the five years of the study we developed an ongoing dialogue that resulted in the development of a framework to guide future modelling. The dialogue took place within meetings and by email.

Joint ownership of key decisions - The public contributors and the research team made joint decisions about what should be included in the framework to guide public involvement modelling through deliberative discussion.

A commitment to relationship building – We believe that the key reason we were able to co-produce the MEMVIE Framework was because we built good stable, reliable, respectful relationships between public contributors and the research team. These were expressed through respectful listening, mutual support and recognition of contribution through ongoing feedback.

Opportunities for personal growth and development – the public contributors had opportunities for personal growth in terms of developing their knowledge of modelling and contributing to research that provided second opinion modelling for the Department of Health and direct input to the Joint Committee on Vaccination and Immunisation. The public contributors were co-authors on the final paper.

Flexibility – We maintained flexibility in what we talked about and the approach we took within meetings. The co-production element enabled us to utilise the idea of a deliberative knowledge space where new forms of thinking are created together through open, non-prescriptive dialogue.

Continuous reflection - Inherent in our approach was continuous reflection. This was built into our continual refinement of the framework and in the discussions we had.

Valuing and evaluating the impact of co-producing research - The use of the concept of a deliberative knowledge space and think-aloud techniques provided an open, non-prescriptive dialogue that enabled ideas and thoughts to emerge. The public contributors were able to challenge the data, the basis for the collection of data and the interpretation of those data, thinking outside of the box in a safe space where modellers could rework their thinking. One of our public contributors stated that the process “was more akin to embarking on a long journey on a complex ship, with no captain, with an unknown destination with no operating manual and a very mixed and unfamiliar crew who were trying to figure out how this ship works, how each crew member fits in whilst trying to write the outline of an operating manual for future passengers on a similar journey”.

The meetings enabled thematic development over time as the Reference Group contributors worked with the academic contributors on continuous iterations of the emerging framework. We held 21 MEMVIE meetings over five years, each lasting between 2–3 hours, with email contact in-between with the group commenting on documents.

Some comments from members of the MEMVIE team describe their reflections on the co-production journey:

Public contributor) “We had no picture of what public involvement would look like, and no route map to guide our journey. We also had no idea of the constraints we might need to work within. The researchers we were working with had no idea of what they wanted from us, or even if we could add anything useful to their model. The first year really felt like working in the dark, not even sure what we were trying to achieve”

(Public contributor) “A key breakthrough was the pictorial representation of the Epidemiological and Economic Model. For the first time we understood modelling as a process and provided a framework through which we could start to organise and structure our contributions”

(Academic contributor) “When I joined midway through the duration of the MEMVIE project, I had not had any previous exposure to public involvement as part of the research process. I found it extremely beneficial to have an additional forum to describe our modelling process, discuss model assumptions and examine data. From my perspective, being given the opportunity to convey the work to public members through reasoned discourse, ensured justification of modelling aspects, aiding model integrity and validity. In

addition, public involvement generated broader discussion surrounding data curation and data collection (such as questionnaire content), producing recommendations that can be used to inform future developments"

WHAT HELPED YOU ON YOUR CO-PRODUCTION JOURNEY?

The key element was having the freedom to undertake exploratory research encouraged by the policy maker who commissioned this work. We did not have a protocol as this would have restricted the study so we benefitted from having the freedom to explore, building on the tenets and practice of co-production. We benefitted from the good relationships developed with the research team and public contributors based on respect, valuing each other and reciprocity.

WHAT CHALLENGES DID YOU FACE IN YOUR CO-PRODUCTION JOURNEY? HOW DID YOU OVERCOME THESE?

The technical and complex nature of modelling meant we had to spend significant time discussing methods and approaches

WHAT LEARNINGS ARE YOU TAKING FORWARD?

We have been encouraged by this initial project and we are now testing our Framework in a follow up study.

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