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# **'A problem shared...' The challenges of public involvement for researchers in Denmark and the UK**

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### **About the Research Unit for User Perspectives**

The Research Unit for User Perspectives (RUUP) is a cross-disciplinary research unit within the Department of Public Health at the University of Southern Denmark. Its main research areas comprise the exploration of user perspectives in relation to: user involvement in healthcare and research, the organisation and practices of the healthcare system, as well as the implementation and use of new health technologies.

(<https://www.sdu.dk/da/brugerperspektiver>)

### **About TwoCan**

TwoCan Associates is a specialist consultancy with over 20 years' experience of patient and public involvement in health and social care research. We make a difference to NHS and voluntary organisations by helping them to clarify the purpose of involvement, to improve their policy and practice, and develop meaningful and effective partnerships.

([www.twocanassociates.co.uk](http://www.twocanassociates.co.uk))

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# Executive Summary

In 2016, the Research Unit for User Perspectives at the University of Southern Denmark embarked on a knowledge-sharing exercise to map the extent of public involvement in research across the country, at the same time as sharing good practice and supporting its implementation. The results of the mapping have been presented elsewhere. The overall picture of involvement in Denmark is highly variable with some institutions carrying out extensive involvement and reporting significant impact, whilst others have only just started and have yet to see a difference.

In this report, we reflect on the more general findings from this exercise that suggest:

- a. researchers experience multiple challenges in implementing involvement
- b. public involvement strategies often lack a clear purpose and are rarely monitored and evaluated
- c. involvement at strategic and project levels are not often linked, so that researchers find that wider research systems and processes (e.g. funders' policies) are not supporting their individual efforts to involve the public in their work

We consider these issues from an international perspective, drawing on our collective experience of working in Denmark and the UK. We conclude that none of the challenges identified in the knowledge-sharing exercise are unique to Danish researchers and therefore represent 'a problem shared' internationally.

We also reflect on the various initiatives being developed in the UK and Denmark that aim to support researchers and highlight additional areas that could be usefully explored. We conclude that these challenges are problems that could be 'halved' through the development of an international strategy to collaboratively address common concerns.

# Introduction

Public involvement\* in research in Denmark began at a strategic level around 2010, when the National Forum for Health Research at the Danish Ministry for Health decided to take a closer look at involvement and established a working group to undertake a review and develop recommendations. This work became visible nationally in 2012, when the Forum published a report on the importance of involving the public in research [1] as part of a wider strategy to increase participation in clinical trials. Although this report advocated wide-scale implementation, the response from the research community was limited at the time.

In 2014, the Ministry for Health and the five regional health providers developed a new policy placing greater emphasis on the delivery of patient-centred healthcare [2]. Involving the public in research then began to gather more momentum, with the recognition that clinical research as part of clinical care, also needed to be patient-focused. In the same year, ViBIS (the umbrella organisation for Danish patient organisations) set up a partnership with the Research Unit for User Perspectives (RUUP) at the University of Southern Denmark in order to promote involvement in research, with one of the authors MH named as Chair.

With the aim of learning from those countries which had already involved the public in research, or were undergoing similar developments, the RUUP consulted a range of international organisations and experts. Table 1 lists the countries and initiatives that have shared, and continue to share, their learning and experience with Denmark. Most often this has included sharing guidance written for researchers and the public, lessons learnt from the implementation of national and local strategies, and recommendations for best practice. Over the past ten years, most of the initiatives taken by the RUUP have been inspired by such international collaboration.

In 2016, the RUUP received a grant from the Danish Board of Health to map public involvement in research across Denmark assessing the extent and reach of this activity. The project took the form of 'knowledge sharing' i.e. collecting information about current practice as well as providing advice to Danish research institutions, through dialogue with researchers and research managers at a strategic level. In this report, we present some of the key findings from this exercise, and report our collective and critical review of the issues raised by senior researchers, finally discussing the implications for a collaborative, international response.

*\*We use the term public to refer to people with relevant experiential knowledge to contribute to research. Depending on the context, this could be patients, carers, potential and current users of services and/or community members. We use the term involvement to refer to the activities whereby these people act as collaborators in research influencing its design, delivery and dissemination.*

**TABLE 1: Sources of international learning and expertise that supported the development of public involvement in research in Denmark**

COUNTRY	LINKS TO EXPERT ORGANISATIONS
England	2010: Visit to INVOLVE ( <a href="http://www.invo.org.uk">www.invo.org.uk</a> ) and four research centres 2010 - ongoing: contact with research centres and involvement experts at the National Institute for Health Research 2012-2017: Participated in three INVOLVE conferences
Ireland	2014: Attended the launch of public involvement in Ireland and since linked with the University College Dublin PPI Ignite Connect network
Perth, Australia	2012- 2017: Links with Involving People in Research ( <a href="http://www.involvingpeopleinresearch.org.au">www.involvingpeopleinresearch.org.au</a> )
Canada	Strategy for Patient-Oriented Research (SPOR: <a href="http://www.cihr-irsc.gc.ca/e/41204.html">www.cihr-irsc.gc.ca/e/41204.html</a> ) – review of published reports and guidance
USA	Patient-Centered Outcomes Research Institute - PCORI ( <a href="http://www.pcori.org/">www.pcori.org/</a> ) – meetings at international conferences
Norway, Sweden, Finland	2014: gave presentation at initial seminar that was the start of the Norwegian national strategy for involvement 2017 - ongoing: joint workshop on involvement in personalised medicine
The Netherlands	2014-15: Visits from a Dutch researcher leading on involvement in rheumatoid arthritis research
EU Joint Programme – Neurodegenerative Disease (JPND) Research – 27 countries.	2014: MH became Chair of the Working Group on public involvement and has developed a strategy for involvement in dementia research with the UK and the Netherlands, which makes involvement mandatory in health and social care research funded by the joint programme ( <a href="http://www.jpnd.eu">www.jpnd.eu</a> )

# Methods

## Knowledge sharing with senior Danish researchers and managers

The approach used to engage senior Danish researchers and managers involved the following steps:

1. Sending invitations to the managers or secretariats of major research institutions asking them to participate in a meeting to discuss public involvement in research
2. Running a meeting with a range of participants, which aimed to address the following questions:
  - Does the research institution have a written strategy for public involvement in research? If yes, how has this been implemented, monitored and evaluated?
  - Does the research institution have specific initiatives/plans for public involvement at an organisational/strategic level?
  - Are there any specific research projects with public involvement in the research institution?
  - What are your positive and / or negative experiences with/attitudes to public involvement?
3. Recording the discussions at the meeting and producing a written record of the main issues, reviewed and agreed by participants.

The institutions that responded to the invitation included hospitals, universities, public and private funders of research, and research centres and units, as listed in Table 2. There are five regions in Denmark for the purposes of organising healthcare. Four of the five were included in this exercise. Information from the fifth, the capital region, had already been collected through prior meetings with individual researchers and institutions. The successful outcome of this approach depended on creating the right conditions for an open and honest dialogue. These are described in the UK's national practice standards for high quality public involvement [3] and included:

- **having good working relationships with the participants** – MH is a well-known and respected senior researcher and national policy adviser, and had already established good relationships with other senior leaders across the Danish research community.

- **ensuring two-way learning for mutual benefit** - the host institutions were asked to decide who should attend the meetings and to agree the final agenda. This meant the participants' interests were addressed as well as those of the knowledge-sharing project. The RUUP team had extensive knowledge and experience of supporting public involvement in research, and when requested were able to provide advice, as well as sharing learning across institutions as the project progressed.
- **fostering mutual trust and respect** - confidentiality and trust were ensured by asking participants to confirm that the written reports of their meeting were accurate, and to agree the points they were willing to share with others. This showed that the lessons from their experience were valued and would also have wider benefit.

Thus the project began to promote shared learning across the research community, which encouraged some institutions to start involving the public, and also led some to make immediate improvements in practice. For example, at one meeting the chair of a board explained the value of a pre-meeting with public members to go through the agenda. This experience was shared at subsequent meetings, which persuaded other researchers to make similar changes to their practice. The project was widely welcomed as one of the first steps in establishing a national network to support the development of public involvement in Danish research.

### **Reviewing the findings from an international perspective**

To foster shared learning internationally, KS was invited to Denmark to present at two major, national meetings where the results of the mapping exercise were discussed with the Danish research community. KS has many years' experience of evaluating the impact of involvement in many different UK research organisations and research projects [4-7]. One of the main findings from the Danish work is that researchers are facing multiple challenges in implementing public involvement. The authors therefore reviewed the details together to consider (a) whether the results from the mapping project revealed any challenges unique to Danish researchers, (b) how well these challenges are being addressed in the UK and Denmark and (c) where there are gaps in the guidance and support for researchers that could be usefully filled.

**TABLE 2: A summary of the institutions that took part in the knowledge sharing project in Denmark**

<b>Hospitals</b>	<b>All five University Hospitals:</b> Aalborg University Hospital Odense University Hospital Zealand University Hospital Aarhus University Hospital National University Hospital /Rigshospitalet
	<b>Two Regional Hospitals:</b> Lillebælt and Sydvestjysk
	<b>Two out of four Psychiatric Hospitals:</b> Southern Denmark and Zealand
<b>University Faculties of Health</b>	<b>All four faculties</b> Aalborg University Aarhus University University of Southern Denmark University of Copenhagen
<b>Research Units</b>	<b>All four units for general practice:</b> Centre for General Practice, Aalborg Section for General Medical Practice, Aarhus Research Unit of General Practice, Odense The Research Unit for General Practice, Copenhagen
	<b>Clinical Research Units:</b> Rheumatology (Odense University Hospital) Orthopaedic surgery (Odense University Hospital) Oncology (Odense University Hospital) Nuclear Medicine (Odense University Hospital) Rheumatology (King Christian X <sup>th</sup> Hospital for Rheumatic Diseases)
<b>Funders</b>	The Danish Heart Foundation The Danish Cancer Society The Velux Foundations
<b>Patient and researcher organisations</b>	Danish Patients - the umbrella organisation for Patient Representative Organisations The Organisation of Danish Medical Societies (Lægevidenskabelige Selskaber) - the umbrella organisation for health researchers

# Findings

## **Mapping public involvement activity across Denmark**

The findings from the project, in terms of mapping the nature and extent of public involvement across different geographical regions and research institutions in Denmark have been reported elsewhere.

A report has been published [8] in partnership with ViBIS, and reflections shared in an article in the Danish Medical Journal [9]. Furthermore, the findings have been disseminated through a series of meetings with research societies, patient organisations and funders in Denmark and at an international conference in the UK [10].

## **Common challenges faced by researchers in Denmark and the UK**

Researchers across all regions of Denmark and across all kinds of institutions asked similar questions and described experiencing the same challenges with involvement. These are listed in Table 3 and relate to:

- The purpose of involvement – why do it?
- Knowing what is best practice
- Knowing who to involve and why
- The skills and experience researchers need to involve the public
- Taking a strategic approach to involvement
- Evaluating the impact of involvement
- Deciding who has power and control in the public-researcher partnership

In the remainder of this section, we discuss the different concerns in turn. We do not attempt to answer the questions, but reflect on how well current guidance and support for researchers is helping them to meet these challenges. We offer suggestions for additional training and support that may prove beneficial. We draw on observations from the knowledge sharing project, our combined experiential knowledge from working for many years in our respective countries, and the involvement literature.

### **The purpose of involvement – why do it?**

The purpose of involving the public in research is commonly understood to be about (a) fulfilling the rights of patients to participate in

decisions that will directly affect them, and (b) ensuring that research outputs will be relevant to the end-users. While supporting these goals, researchers are often left wondering why *they* would want to do it and how it will benefit their specific project [11].

A crucial question for any person thinking about taking action to change their behaviour is ‘What’s in it for me?’ This question has been addressed for patients who have often described the personal benefits of being involved [12,13]. We believe the same question needs to be asked of researchers with experience of involvement. Understanding and sharing the benefits for the researchers (rather than for the research) may prove to be another powerful motivator [6].

### **Knowing what is best practice**

We are aware that very many documents describe best practice and that considerable evidence has been published on this issue [3,14-17]. However, much of this guidance is generic and researchers are not always clear how to apply the general advice to the specifics of their situation. Further work which is piloting the UK’s national standards is aiming to help with this challenge [3]. From the perspective of a researcher, it is still difficult to navigate through this very crowded field to find answers to specific questions. An online resource which signposts researchers to the most relevant guidance and sections of key documents would be of great value.

However, in our view, written guidance has its limitations. We suggest learning how to involve the public is much more about ‘learning by doing’. By way of analogy, there’s only so much to learn from reading information about how to ride a bike. It’s more important to gain confidence through repeated practice.

We conclude that greater emphasis should be placed on providing researchers with practical support from people with more experience, who can mentor or help the individual when they first involve the public, and subsequently help them to improve and extend their practice over time. We suggest that work is needed to explore how best to provide this kind of support and to create more opportunities for shared learning between researchers [18].

### **Knowing who to involve and why**

Our conversations with researchers in Denmark and the UK, often reveal confusion about when patients need to be involved and when involving members of the public may be more appropriate. The terms used for involvement have not helped to clarify this issue [19]. In the past, ‘patient-and-public-involvement’ was often used as if it referred to a single activity. Now the common use of the term ‘public involvement’ risks underplaying the significance of working with different

kinds of experiential knowledge. The factors that determine whether patients or the public need to be involved in the development of health services have been recently described [20] and we support others in calling for further work to understand these distinctions in relation to involvement in health and social care research [11].

### **The skills and experience researchers need to involve the public**

The Danish senior researchers were clear about the training they thought would most benefit them. At the beginning, they wanted to be informed about what involvement is, how it works, and its benefits and challenges. Then they wanted training to develop ‘soft’ skills, in particular learning to facilitate groups, as has been reported elsewhere [21]. Training and support for researchers are areas that have received relatively little attention in comparison to training for the public [22] and one which we believe requires further exploration.

We also hear researchers expressing common misunderstandings and assumptions about involvement, even after receiving training. Researchers sometimes want to implement involvement in much the same way that they might think to implement a healthcare intervention or conduct qualitative research. We are often asked for the ‘best method for involvement’, for sources of ‘robust evidence of effectiveness’, and ways to ‘measure impact’. By way of contrast, we understand involvement as a conversation that supports two-way learning between researchers and the public [6,23]. With this framing, it becomes clear that there are no ‘methods’ but different techniques which may be more or less useful in different contexts, and that the outcome is subjective and unpredictable [23]. We conclude that future training could aim to correct these assumptions and do more to influence the researchers’ mind-sets, to better prepare them to learn from involvement and to be responsive to what they learn.

### **Taking a strategic approach to involvement**

In general, the Danish institutions’ reports of involvement appeared to be focused on process, rather than any particular strategy to achieve a desired outcome. They reported inviting one or two members of the public to join an existing council or committee, or having set up new group. Sometimes this was a group with responsibility for governance, and sometimes it related to the research function of the organisation. Overall, it seemed that simply ‘doing involvement’ had become a goal in itself, rather than involvement being recognised as a means to achieve mainstream aims and objectives [24]. This emphasis on process over strategic outcome also appears to be common in the UK. Many research institutions’ involvement policies are very similar, while the responsibilities of these institutions are very dif-

ferent, and arguably the strategic approach to involvement may need to be distinct in these different contexts (unpublished observations).

Few of the Danish institutions had written a strategy for involvement and those that had, could not always describe how it was being implemented. It seemed that a great deal of effort had been made to develop strategies with considerable involvement of a range of stakeholders, but without in-built monitoring or evaluation, these strategies had failed to direct action. Close follow-up work seems to be essential for an involvement strategy to be meaningful and to lead to change.

Another important finding was that the senior researchers at the top of Danish institutions were often unaware of the involvement taking place at the lower levels of their organisation. The RUUP is aware of considerable involvement in individual projects in Denmark, as they receive multiple requests for advice from researchers. However, it seems as if involvement at strategic and project levels, is rarely, if ever, connected. Without this linkage, researchers can feel that systems and policies, both within their own institutions and across the wider research community, are not supporting their involvement work [25].

For example, some funders in Denmark have recently introduced a requirement for involvement as a condition for funding, but as yet there is no consensus amongst funders and applicants as to what 'good' involvement looks like. Other studies have reported that researchers expect their managers and those in funding bodies to be developing new policy and processes to support involvement, but it is not clear that the senior managers/researchers always share this understanding [26]. This is again an important area for further development work to ensure that future strategies address what needs to happen at all levels and in all parts of the research system, to ensure a consistent and coherent approach to involvement.

### **Impact of involvement**

The overall picture of the impact of public involvement in Denmark is one of huge variability. For example one hospital had been involving the public for many years and senior researchers reported this had led to a dramatic change in their research portfolio. They had changed from being a research unit with an almost exclusive focus on clinical intervention projects, into a unit carrying out many different types of research. By way of contrast, other organisations had only just started involving the public and had yet to report any change. Knowing how best to capture and report the wide range of impacts of involvement has been a challenge for everyone working in this field for many years. Again, this is a topic of intense activity in the

UK, and an international conference on evaluating impact took place in Newcastle in the UK, in 2018 [10]. As yet, there does not seem to be consensus on the ‘why’ or the ‘how’, and we anticipate this debate will continue. We note that impact is most often described in relation to individual research projects, and there has yet to be a discussion of what success looks like in terms of involvement in research governance or developing research strategy.

We believe this is important to inform future involvement strategies (see above). It would also help members of the public, who are often involved at different levels, to be clear about their roles and responsibilities in different contexts, as well as how these activities might be linked.

### **Deciding who has power and authority in a public-researcher partnership**

Based on the questions from many researchers in Denmark and the UK, we believe this is an area of great controversy as well as considerable misunderstanding. It seems that some researchers have assumed the gold standard is to be ‘public-led’ and that this means ‘doing whatever the public suggests’, even if this is contrary to professional opinion. While involvement does require sharing power in decisions about what research gets done and how it gets done, the boundaries of the respective roles and responsibilities of public and researcher partners have not been clarified or agreed [28,29]. It seems researchers have not been prepared or equipped to navigate the complexity of this new way of working. We conclude this is an important aspect to incorporate into future training for researchers.

Some researchers remain unclear about how to manage situations in which the involved member of the public is unhelpful or perhaps unable to follow through in their involvement role, even after receiving training and support (for example, if they prove not to have the skills required of a qualitative interviewer [30]). Researchers are mindful of the need to be respectful of the public perspective and to welcome constructive criticism, which can leave them deeply uncertain about whether they can be critical of the public’s contributions. Since members of the public are not employees, researchers are unclear of what authority they have to set standards and manage the performance of the people they involve, should this prove necessary. They would benefit from advice on how to manage these sensitive situations, which is again another topic that could usefully be included in researchers’ training.

**TABLE 3: Questions/ concerns raised by Danish researchers**

	<b>QUESTIONS/ CONCERNS FROM DANISH RESEARCHERS</b>
<b>The purpose of involvement – why do it?</b>	<p>Do the public have a right to be involved?</p> <p>Does involvement help to avoid waste in research by ensuring that it focuses on issues of importance and benefit for the public?</p> <p>Should involvement be made mandatory for funding or publication?</p> <p>What are the rewards for researchers who do it well?</p>
<b>What is best practice?</b>	<p>What are the best ways to recruit patients and members of the public? Should patient organisations help with recruiting patients and carers to be involved?</p> <p>How many patients should be involved - in research projects, research councils, or patient panels?</p> <p>How do we ensure that vulnerable patients get a voice? How do we reduce inequality and increase diversity amongst those involved?</p> <p>What training, support and information do researchers need to give to the patients they want to involve?</p> <p>In what parts of the research process is it relevant to involve patients?</p> <p>Should we pay patients for being involved? If yes, how much and how do we avoid an impact on benefits? How can we do this during the development of a new project when we don't yet have funding?</p>
<b>Who to involve and why</b>	<p>Do patients need to have a particular kind of experience to be involved?</p> <p>When do we need to involve specific kinds of patients, any kind of patient and/ or members of the public?</p> <p>Who should we involve at a strategic level, e.g. in research councils?</p> <p>How do we train and support patients/ the public in this role?</p> <p>How do we ensure diversity amongst the patients and public we involve?</p> <p>How do we involve the people who are seldom heard?</p>
<b>The skills and experience researchers require for involvement</b>	<p>What initial training and ongoing support do researchers need?</p> <p>Most do not know how to involve patients and do not know what patients can contribute.</p> <p>How to manage group discussions to allow people to have their say, but also keep the discussion focused?</p>
<b>Taking a strategic approach to involvement</b>	<p>How should involvement be organised within an institution to join up the activity at a strategic level with involvement in research projects?</p> <p>How do other stakeholders who are also end-users of research (e.g. health professionals) need to be involved? How does this fit with patient involvement?</p> <p>Is it meaningful to invite one or two patient representatives to become members of an organisation's strategic committees?</p> <p>Is it relevant to involve patients in all types of research?</p> <p>Should patients be involved in basic research or health data related research?</p> <p>What does successful involvement in the governance of an institution look like?</p>
<b>Impact of involvement</b>	<p>How do we measure the impact of involvement? Is this possible with all types of involvement?</p> <p>What is the evidence for positive impacts of involvement in the individual phases of the research process? Where in the research process it is of greatest value to involve patients?</p> <p>How do we evaluate involvement in a way that allows us to improve our practice?</p>
<b>Who has power and authority in a patient-researcher partnership?</b>	<p>Should researchers always do what the patients tell them to do?</p> <p>If all research is driven by patients' interests, does that mean the end of 'blue-skies' research which may not have an immediate, practical benefit?</p> <p>How do we avoid tokenism in involvement?</p> <p>How do researchers need to manage situations when patients make unhelpful contributions, or find they are unable to do the task they are involved in?</p>

# Conclusions

The knowledge sharing exercise in Denmark has revealed a complex picture of how involvement in research has evolved over the past few years. While there are many examples of excellent work which have already resulted in meaningful and significant change, there still seems to be considerable uncertainty amongst researchers around the 'why' and the 'how'. None of the questions asked by researchers are a uniquely Danish concern. The same questions are often asked by researchers in the UK. Previous reports have suggested there may be a particular Danish problem in finding appropriate translations for the terms 'involvement', 'engagement' and 'participation' in a way that makes sense for Danes [31]. However, the challenge of precisely defining these terms is universal. They are often used interchangeably and inconsistently in English [19].

We suggest that the perfect terms may never be found, and perhaps the more important issue is ensuring that when teams of researchers and the public work together, they all have a shared understanding of the terms they choose to use. This will be true for all languages and for all countries.

The crucial question is then how to respond to the observed variability in the quality and impact of current practice. We conclude this is 'a problem shared' and could become 'a problem halved' if international collaborative work were to take a strategic approach to finding common solutions.

Historically, INVOLVE in the UK has often led the involvement field and has broken a lot of new ground. Under the direction of the National Institute for Health Research (NIHR) National Director for Patients, Carers and the Public, work is now underway in the UK to tackle some of the outstanding challenges [32]. Two major pieces of work are being undertaken to develop ways to assess the impact of involvement and to increase the diversity amongst the people who get involved in research. However, as this Danish project has revealed, there are many other challenges that still need to be addressed. As other countries are building their capacity and expertise in involvement, there are opportunities for them to take on complementary areas of work and to share their learning more widely, for example through the International Network for Public Involvement and Engagement in Health and Social Care Research. MH is a member of the planning team for this Network which was launched in November 2017, and since received expressions of in-

terest from over 200 organisations and individuals. The Network's vision is to aim for a world where patient and public involvement is an integral part of health research. To accomplish this mission, the network is aiming to build a global partnership that shares knowledge and promotes, supports and strengthens involvement in research.

For Denmark, as for other countries, one of the key questions to address is 'What kind of infrastructure is needed at national, regional and/or local levels to support an expansion and improvement in involvement?' Does every country need the equivalent of INVOLVE? We suggest that an evaluation of the effectiveness of the infrastructure in different countries' would be of great value, sharing the learning internationally so as to avoid reinventing the wheel.

There may not be value in simply duplicating what already exists in the UK, if much of the foundation work can be shared, and new approaches might be better suited to addressing fresh challenges. Experience from the UK suggests that creating system-wide leaders for involvement at a national level is important to connect up the different parts of the research system and ensure a co-ordinated and coherent approach to involvement. MH has informally filled this type of role in Denmark, from his base at the RUUP.

Our overall sense of the variability in involvement practice is that there are more differences across the research community within a country, than there are across the research communities in different countries. It often seems to depend on the skills and level of experience of the researchers' and their preparedness to learn. We see value in aiming to adapt future support for researchers in order to meet a wide range of learning needs. For example, while new researchers may continue to benefit from introductory sessions, more experienced researchers may need Masterclasses or tailored support to find ways to enhance their practice.

An important part of the solution to improving practice is to enable researchers and the public to learn from one another. As a small country, with a much smaller population (approximately 10% of that in the UK), the Danish research community is already well-connected. The Danish national context therefore offers huge potential to create involvement networks to support learning 'from the bottom up'.

The knowledge sharing project represented the first step in building such networks, and the RUUP intends to continue working with researchers at all levels, as well as the public, to continue to develop a national network 'Patient as Partner in Health Research', that will meet different stakeholders' needs. It will also be important to find ways to monitor and evaluate this initiative.

Continued international collaboration is vital for expansion and im-

provement in involvement practice. We note that some of the early Danish adopters had previously worked in the UK or the USA, or were collaborating with researchers from these countries, and this had influenced their decision to involve the public. As a counterbalance to the ever increasing volume of written guidance and toolkits, we suggest that efforts be made to support more of this person-to-person collaboration, to create international networks to share learning at project and strategic levels. We conclude there is as much to gain from sharing our common problems and challenges, as there is from identifying what works well.

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