

INVOLVE

Conference 2010

**Public involvement in research:
innovation and impact**

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East Midlands Conference Centre, Nottingham

Conference Report

INVOLVE

**Supporting public involvement
in NHS, public health and social
care research**

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1. Introduction

Purpose of the conference

INVOLVE's national conferences bring together people with a common interest in public involvement in NHS, public health and social care research. This includes members of the public, service users, researchers, research commissioners, advisers and representatives of voluntary sector organisations. The aim is to encourage the sharing of knowledge and learning.

The focus of this 7th Biennial Conference was innovation and impact including:

- the ways in which the public are involved in research - new approaches
- understanding the impact of public involvement - how it makes a difference
- providing a platform for research on public involvement in research

The conference took place over two days on Tuesday 16th November and Wednesday 17th November 2010.

Conference delegates

The conference attracted more delegates than ever before with a total of 438 people attending over the two days. Delegates were drawn from a range of backgrounds as the list below shows.

How conference delegates described themselves	Number (%)
Researchers	117 (27%)
Research commissioners, advisers, research development	65 (15%)
User researchers	37 (8%)
Members of the public, service users and carers	108 (25%)
Voluntary sector organisations	36 (8%)
INVOLVE Group members and Coordinating Centre	36 (8%)
'Other' (including public involvement leads, administrators, journal editors, practitioners, clinicians, students)	35 (8%)
Not given	4 (1%)
Total	438 (100%)

Overview of the conference

The conference covered a wide range of issues relating to public involvement in research with opportunities for delegates to contribute, learn, discuss and debate. In all there were 50 papers presented, including two keynote speakers, 47 posters displayed, 20 different workshops or discussion sessions, an information session, a 'soapbox' session and 5 'next steps' workshops.

Included over the two days there were:

- illustrations of public involvement and partnership working between service users, researchers, commissioners and practitioners
- explorations of new approaches, development of ideas and lessons learnt
- a focus on researching, evaluating and reporting the impact of involvement in research
- examples of involving communities and specific groups of people in research, and
- projects highlighting user-led research.

A number of issues cut across these areas including support and learning for involvement, how to measure and report the impact of involvement, international perspectives, current policy and service changes and how they link with public involvement in research and future directions.

The next sections of this report summarise the keynote speeches and describe in more detail the content of the conference.

2. Conference summary

Welcome

The conference was opened by Sir Nick Partridge OBE, Chair of INVOLVE and Chief Executive of the Terrence Higgins Trust. Nick welcomed delegates to the conference at what he called 'this extraordinary time' with changes taking place across health, social care and public health, as well as within universities and in how research is funded and assessed. He urged us to ensure that the patient and public voice is continually heard, and talked of his encouragement at the number of people taking part in this conference.

Nick introduced both of the plenary sessions, which included the opening speech by Russell Hamilton from the Department of Health and the closing speech by Simon Denegri of the Association of Medical Research Charities (AMRC).

Opening keynote speech: Reflections on public involvement in health and social care research

**Dr Russell Hamilton CBE, Director Research and Development,
Department of Health**

Dr Russell Hamilton opened his keynote speech saying this was probably the most important conference that the National Institute for Health Research (NIHR) sponsors throughout the year. One of the early members of INVOLVE, Russell is now Director for Research and Development at the Department of Health where his work focuses on the development and implementation of policies and strategies to ensure that research improves health and healthcare. He played a key role in the creation of NIHR and is now engaged in developing a research system in the NHS that supports world-class research and is focused on the needs of patients and the public. His speech to the INVOLVE conference focussed on why he supports patient and public involvement in research, why the government does and why NIHR does.

He began by sharing why he is interested in patient and public involvement. He explained how he believes passionately that involvement is essential to high quality research and that high quality research is key to the health service. He has long been an advocate for involvement and now promotes it throughout his work. He believes it is important because it increases research quality with better questions, design and analysis, and because it increases relevance by reflecting patients' needs, outcomes and preferences. Through the innovation and impact which involvement brings, research uptake increases.

Russell then spoke about why the government supports involvement. He referred to the Department of Health's recent 2010 White Paper 'Equity and Excellence: Liberating the NHS' which refers to research as a core part of the NHS. In the recent Spending Review, the Chancellor specifically talked about protecting health research funding because the government believes that investing in research is key to improving health. Furthermore, Earl Howe, Parliamentary Under-Secretary of State in the Department of Health (July 2010) has highlighted the importance of on-going government support for NIHR's work involving patients and the public in research.

Public involvement runs throughout all parts of the NIHR and patients and the public are at the centre of its organisational structure. NIHR's support for patient involvement includes providing money to enable it to happen, as well as guidance on how best to involve the public and funding for INVOLVE itself.

Public involvement in NIHR's work can also be viewed in terms of the research cycle, and Russell gave examples of identifying and prioritising research agendas through the NIHR Advisory Board, the UK Clinical Research Collaboration (UKCRC) www.ukcrc.org and the work of NIHR's partner bodies such as the National Cancer Research Institute. Examples of patients and the public prioritising specific research questions can be found at the James Lind Alliance, the Health Technology Assessment programme and the NIHR's School of Social Care. Patients are involved in research commissioning as reviewers of research applications. Furthermore by requiring grant applicants

to specify how they will involve the public in their research, such involvement in the conduct of research is encouraged.

Support in planning involvement is also provided to research applicants via the NIHR Research Design Service. The implementation of this planned involvement is also facilitated by NIHR with large numbers of patients and the public playing an active role in Clinical Research Networks, and both Biomedical Research Centres and Units. Describing the patient involvement in projects is also increasingly required in research reports. Working with Collaborations for Leadership in Health Research and Care (CLAHRCs) provides a key bridge to getting patient-informed and patient-involved research into practice. Lastly, NIHR are investing in monitoring and evaluating involvement to increase our understanding of all of this work.

Russell finished his speech by stressing that involvement requires all of us. Challenges remain in encouraging others to see the value of involvement, in gathering evidence of what works well and why. NIHR has confirmed its commitment to public involvement in research and we now all need to work with other's to ensure they do the same.

The PowerPoint slides of Russell Hamilton's speech are available at www.invo.org.uk/conference.asp

Presentations and posters

With a record number of presentations and posters at this year's conference, delegates were able to choose from a wide range of sessions. There were examples of involvement in research across health, social care and public health, including service-users' own accounts of their involvement. Reported activities spanned research designs and used a range of models for involvement, with examples from throughout the UK and further afield. In addition, delegates learned of a number of structural programmes to support and facilitate involvement, both within NIHR and across other institutions. There were presentations and workshops designed to inform and train participants in a range of topics. Presenters also focussed on the cross-cutting principles of involvement and explored underlying theories. Last, but by no means least, was a focus on the impact of patient and public involvement in research – how and why it might be measured and what the state of the evidence base is so far.

Examples of involvement in research across health and social care

Conference presentations included detailed examples of patient and public involvement in a range of research projects.

We heard about involvement in research into alcohol dependence, challenging medical models of 'alcoholism', research about rheumatology, with a presentation by researchers at VU University in Amsterdam, and a number of presentations on mental health conditions, managing chronic back pain, developing foot pain research, kidney care and cervical cancer. There were projects about childhood disabilities and about the lives of young people, specifically on bullying and work at the London School of Hygiene and Tropical Medicine in partnership with young students about the public health benefits of free public transport for young people. Older people were also involved in research about their health and social wellbeing, including conducting peer-to-peer community research in partnership with Age Concern.

Projects explored rehabilitation after a stroke, including assistive technologies to aid walking and interventions for continence, as well as broader research into habilitation for hearing aid users and the use of Telehealth to enable people in need of social services support to keep living in their own homes.

As well as patients and carers with direct experiences of these various conditions, and the users and potential users of related services, we heard about the involvement of specific groups of people. These included young people, for example in the work of the National Cancer Research Institute's Teenage and Young Adult Clinical Studies Group, as well as 'seldom heard groups', older people with dementia and people from black, Asian and minority ethnic communities.

We heard about involvement spanning a wide range of study designs including meta-analyses, a range of qualitative research designs and, perhaps particularly noticeable at this conference, an increased number of examples presented of involvement in clinical trials. These included involvement in a trial exploring the best ways of following-up women who have been diagnosed and treated for breast cancer, involvement in trials at the Medical Research Council Clinical Trial's Unit, and work at the Institute of Psychiatry at King's College London to identify patient and nurse generated outcomes in mental health and ensure their inclusion within a trial of acute wards.

The examples presented also covered different degrees of involvement – from consultation to 'co-production' of research through to user-led research. The latter included work commissioned by INVOLVE to look in detail at seven examples of user-controlled research. A wide range of approaches to involvement were described from committee membership, to focus groups, such as those used by NIHR's Evaluation Trials and Studies Co-ordinating Centre, and 'community of practice' approaches. There was also discussion of how involvement varies internationally, with examples from Australia, North Korea, Japan, the Netherlands and the USA.

Specific presentations gave user-perspectives on their involvement in programmes including a user-perspective of a Forum set up at Lancaster

University to enable users to become involved in research activities. Members of the Lay Advisory Panel for Bone Research which works with the NIHR Bone Biomedical Research Unit also shared their experiences and a volunteer who has participated in a number of trials shared his experiences, including the expected and the more surprising side effects of getting involved. Lastly we heard first hand experiences of users involved in mental health research.

Structures to support and facilitate involvement

There were a striking number of presentations and posters about programmes to support and facilitate patient and public involvement in research. These included reports of involvement within the following NIHR networks or groups:

- NIHR's Mental Health Research Network's FACTOR group (Families / friends and Carers Together in Research);
- NIHR's Clinical Research Networks;
- NIHR Biomedical Research Centre in Oxford's development of a patient and public involvement strategy and a Research Interest Group to facilitate involvement within the clinical research environment;
- NIHR's Evaluation, Trials and Studies Co-ordinating Centre (NETSCC)'s use of a pilot focus group to inform the decisions made by its Public Health Research Programme Advisory Board;
- NIHR's Policy Research Programme Central Commissioning Facility's use of focus groups;
- NIHR's National Cancer Research Network collaboration with the National Cancer Research Institute to develop a co-ordinated approach to patient and public involvement in cancer research;
- NIHR's Diabetes Research Networks PPI programme's establishment of regional reference panels of people affected by diabetes to bring patients and carer perspectives to research prioritisation and study design; and
- NIHR's Research Design Service (with examples of initiatives in particular regions) referring in particular to the work of PPI leads and the bursary schemes that they run to enable researchers to involve the public in the development of research funding applications.

Further presentations and posters reported on other programmes to support involvement in research including: the National Cancer Research Institute's Teenage and Young Adult Core Consumer Group; a forum which spans Leicester, Northampton and Rutland with the aim of facilitating patient and public involvement through multi-agency working; the development of an innovative Kidney Research and Education Initiative informed by service-users and carers; a Donor/Lay Forum which is being set up by the National Cancer Research Institute's Confederation of Cancer Biobanks to bring the lay/patient perspective to biobanking; the development and implementation of regional patient and public involvement in research strategies in South Yorkshire and also in the North West; the Service User Research Forum of the Healthcare Associated Infection Research Network; involvement within the National Institute of Social Care and Health Research's Clinical Research Centre in Wales; the work of Folk.us, a Devon-based organisation which brings together researchers and service-users; and involvement in the Peninsula Collaboration for Leadership in Applied Health, Research and Care in the South West of England.

Information and training about involvement

The conference included several opportunities to learn from one another through discussion and sharing, with some sessions dedicated specifically to this. These covered how best to include particular groups of people, such as young people, and specifically how to be inclusive and engage with 'seldom reached' groups. One presentation by researchers from Warwick Medical School described how photography has been used to capture the needs of often neglected populations. There was also information about how best to include patients and the public in developing research proposals in appropriate and meaningful ways, how to get funding for user-led research, and how patients can contribute to the development of clinical guidelines. We also learnt about how charities can help facilitate lay involvement, using the example of Epilepsy Action's Research Network.

There was an opportunity to build links with other conference delegates via a facilitated networking session, with introductions, discussion and debate about

involvement in research. There was also an information session about the work of INVOLVE, as well as the screening of a series of short films commissioned by INVOLVE about user-controlled research, and a session dedicated to the history of involvement in research in the UK. We learnt of resources available to support involvement including a route map for those responsible for prioritising, commissioning and overseeing research, a web-based resource for those with responsibility for user involvement, and a proposed code of ethics for patients and public involvement in research design.

The ideas underpinning involvement

The conference also included presentations which aimed to explore the principles, practices and impacts of involvement in a more theoretical way. Delegates were invited to reflect on the roles that patients and the public play in research and what makes them credible in health research settings. They discussed what constitutes knowledge and how different types of knowledge influence policy and practice and engage in critical debates about involvement, its benefits and costs. There were presentations on the ethics of involvement and frameworks were proposed to describe patient and public involvement in the process of getting research into practice, and to evaluate the impact of involvement.

The impact of involvement

Last, but not least, there was a focus at the conference on the impact of involvement on those involved, on the research in which they are involved, and on the health and social care services they seek to improve. In a series of presentations delegates were invited to explore the values and philosophy behind impact and consider whether there are different, competing and even conflicting understandings and ideologies of impact. There was an opportunity for frank discussion about who is interested in measuring impact, and whether it is necessary or even possible. A number of proposals were also put forward on how to evaluate involvement including a theoretical framework which incorporates the degrees and models of involvement.

There were also reports of impacts on individual projects and programmes. These were largely based on reflections and observations of the research team, including the patients and public who were involved in projects. We heard about increasing participation in research and a greater sense of engagement and well-being amongst those who get involved. Patients and the public brought new perspectives to some research teams, increased the relevance and gave greater credibility to the research. They also highlighted important gaps in the research, particularly relating to the outcomes being measured and in one case also helped to tailor the intervention in a trial enabling a more meaningful evaluation to be conducted. Patients also improved the conduct of trials, helping to smooth the ethics application process and achieve the target recruitment. In doing so they also saved the trial team considerable costs. Lastly we heard of one study influencing NICE guidelines, made possible largely because of the effective patient involvement in the research. These studies also spoke of the barriers to having an impact on research, including practicalities such as the timing of decision-making and the time and cost required for meaningful involvement.

There were also presentations of reviews which aim to summarise and synthesise evaluations of impact. The first of these, conducted by a researcher at the University of Warwick, focussed on understandings of involvement and definitions and measurements of impact. The review suggests that whilst a common understanding of involvement exists, conceptual and theoretical underpinnings are scarce. Impacts are largely being captured in descriptive ways, with some indications of cost. A second review by researchers at the NIHR Research Design Service in Yorkshire and the Humber examined seven examples of public involvement in the design of health research with a focus on what impacts they have had. Across the examples presented, impacts included revising consent procedures and information sheets, suggesting outcomes to measure, reviewing the acceptability of data collection methods, and making recommendations on the timing of involving participants in the study.

Delegates also discussed INVOLVE's 'Exploring Impact' report, published a year ago, which identified a variety of impacts, including impact on the research at various stages, and on the members of the public involved in the research, the researchers and the organisations and communities with whom they work. It also found that involvement can influence whether the results of research have been used to bring about change. Lastly, there was a session focussing specifically on the reporting of the impact of patients and public involvement in order to strengthen the evidence-base of involvement.

Closing keynote speech: The rise and rise of public involvement: what's stopping us?

Simon Denegri, Chief Executive, Association of Medical Research Charities (AMRC) and a member of INVOLVE

Simon began by congratulating INVOLVE on an excellent conference and talked of looking upwards to the next challenges and opportunities and his optimism for the future.

He talked of the new coalition government and the importance of context, something which INVOLVE has always been very responsive to. He described how much has changed since the first INVOLVE conference in 1998 with regards to how government viewed patients and the public and the importance of research. Despite these positive changes, the current context is more uncertain. Changes to university funding and the wider research environment will make on-going financial support for public involvement in research more uncertain.

Simon spoke of the planned reforms to the NHS. He referred to the importance of questioning and scrutinising the statement in the Department of Health's recent 2010 White Paper 'Equity and Excellence: Liberating the NHS that 'no decision will be taken about us, without us'. He highlighted two key issues of concern to patient and public involvement. The first is the leading role that general practitioners will play in the new NHS - there are relatively small numbers of GP practices engaged in research, the available resources are

limited, and attitudes amongst GPs are not generally conducive to patient and public involvement. The second is the uncertainty about how research within the new system will be encouraged.

In response to these challenges, Simon proposed a number of strategies. He acknowledged INVOLVE's work and the strength of the grassroots of public involvement and stressed the increasing importance of championing patient and public involvement in the right places, on committees and boards within the NHS. He spoke of changes to the regulation of research, of how the AMRC and INVOLVE have been contributing to what the new structures might be, and the importance of continued pressure on government for stronger models of public involvement in research regulation. What we want, he suggested, is a National Health and Research Service.

In talking about the current political environment, Simon added an aside about the 'Big Society' and noted that whilst it sounds very positive, it is also poorly defined and needs challenging and debating.

Simon moved on from discussing the current environment in which we are working, to suggest three ways in which we continue to grow.

The first way in which Simon suggests we can continue to grow is by 'staying close to our public'. He stressed that it is by working closely with their respective publics that AMRC and their member charities have thrived. It is this close engagement with patients and the public which drives our purpose and vision and provides strength.

Simon's second proposal is through 'connectivity'. He talked about the huge range and number of public involvement activities throughout the UK and the need now for more formal networks to enable greater awareness of what is going on – informal contacts are no longer sufficient. He referred to the role that AMRC plays as a central reservoir serving many different communities of practice within medical research charities, and suggested the need for new organisation of patient and public involvement activities.

Thirdly, Simon spoke about the strength of partnerships and their importance in the current climate. He suggested that we have only begun to scratch the surface in terms of what INVOLVE and AMRC and many others can achieve through partnership.

Simon's final message was that we must continue to seek to persuade others through evidence of our impact as a community. He talked of remaining positive, persistent and patient in providing sceptics with the evidence of how public involvement makes a difference and why it makes or can make UK research better.

A full transcript of Simon Denegri's speech is available at www.invo.org.uk/conference.asp

3. Other contributions to the conference

A chance to share burning issues

Delegates had a range of opportunities to raise issues for discussion. As well as the question and discussion sessions at the end of presentations and posters, people were invited to note down 'burning issues' and post these on a specially provided noticeboard. A 'soap box' session, facilitated by Lester Firkins from the James Lind Alliance, gave delegates a further opportunity to take the floor for 3 minutes and have their say. The wide range of issues raised are summarised below:

- A reflection about the political climate and whether those delegates who rely on health and social care services and financial benefits will be able to attend the next conference;
- A question about the availability of and need for those with specialist research skills alongside and in addition to service-user researchers;
- Calls from service-users for better feedback about the activities in which they take part including research projects and even conferences such as this one;
- Calls from researchers for better feedback from funding bodies;
- Challenges to the Research for Patient Benefit Programme about its name, the clinical model it portrays and the practical hurdles of applying for grants;
- Requests for better information on what research is taking place and about what involvement activities are taking place;
- Suggestions for novel ways of communicating with the public about research such as the development of a DVD;

- A challenge as to whether user-controlled research is a positive step to balance the lack of patient involvement in much research, or another form of discrimination;
- Calls for self-reflection about what works and promotion of sharing personal stories about impact to contribute to the growing body of evidence;
- Questions and opinions about involvement in research about specific topics including life-style, mental health, cancer and alcohol dependence;
- Requests for help in how to input ideas for new technologies based on patient experience;
- Questions about payment for involvement and calls for clarity and guidance;
- Support for working in partnership with other organisations; and
- Practical suggestions for the conference, observations about the profile of who attends, and suggestions for 'levelling the playing field' so all can attend on an equal footing.

Opportunities for involvement

This year the conference invited organisations to publicise opportunities for patient and public involvement on a dedicated information board. Twenty-three different opportunities were advertised from a wide range of organisations. These included calls for those with a family history of conditions, direct experience of service provision, or merely an interest in sharing their views as members of the public and 'potential' service users. The range of conditions included cancer, Alzheimer's and other dementias, thyroid conditions, eye problems, heart conditions, mental health conditions, pressure ulcers, epilepsy, respiratory conditions and pregnancy. The notice board included invitations to take part in specific research projects on these topics and more general requests for patients and the public to contribute to setting research agendas, the commissioning of research, research design, and the regulation

and monitoring of research. Further information about these and other opportunities can be accessed through People in Research at <http://www.peopleinresearch.org>

4. 'Next steps' workshops

The conference closed with five workshops on different topics, each looking to the future. Each is outlined briefly below.

Count us in! Involving everyone in health and social care research

Facilitated by Patsy Staddon, Lucy Simons, Hasmukh Metha and Jan Wallcraft, this workshop sought to build on a report published earlier this year of service users' perspectives on the barriers to achieving greater inclusion in research (see 'Count us in! Involving everyone in health and social care research' available from www.shapingourlives.org.uk).

Following an initial discussion in which the facilitators shared their experiences of being involved in research, the delegates at this workshop split in to two groups: service-users were asked to focus on what messages or information they thought should be conveyed to researchers about inclusion and diversity, whilst researchers considered what information they would find helpful in a guide on the topic. The resulting key messages were recorded and will be used to inform INVOLVE's work to up-date information for researchers about why and how to actively involve a diverse and inclusive range of people in research.

Hot tips surgery for researchers

Facilitated by Tracey Williamson from the University of Salford, this workshop focussed on enabling delegates to discuss freely the difficult issues arising in involving patients and the public in research. Prompted by mini-case studies of real-life issues faced, delegates shared their stories.

The discussion was wide ranging, with open and honest discussion of the tensions and conflicts which can arise covering both practical issues and more theoretical ones. Whilst the session raised many challenging issues, it also provided an opportunity to discuss possible solutions and share positive stories.

Writing up research for publication

Facilitated by Tina Coldham, Health Service User Trainer, Researcher and Consultant and Sian Maslin-Prothero, Professor of Nursing at Keele University, this practical workshop aimed to support participants in writing for publication. With the increasing emphasis on involving service users in writing up research and in reporting the impact of involvement, this workshop enabled delegates to discuss their ideas for writing.

Activities included exploring reasons why you might want to write and planning writing in different styles and for different audiences from a party invitation to a conference abstract. By the end of the session everyone was encouraged to write themselves a writing action plan, laying out what they want to do, how they might do it, the resources they might need and the first steps to making it happen.

Training and support: Where next?

This session was facilitated by David Evans, INVOLVE Group member, Bec Hanley and Kristina Staley of TwoCan Associates and Rachel Purtell, the Director of Folk.us. They focussed on current progress in training and support for involvement. Delegates heard about developments within INVOLVE and at Folk.us, as well as sharing information about what they have been doing. The session closed with a 'next steps' discussion about how training and support might be further developed in the future.

What to do when things go wrong: Developing good practice

Anne McKenzie, Consumer Advocate from the University of Western Australia and Philippa Yeeles, Deputy Director of INVOLVE, facilitated this session which invited delegates to explore the development of good practice in situations where the planning and delivery of public involvement activities had gone wrong. Working in two groups, each group was given an imaginary scenario based on a composite of real situations and asked to consider:

1. How would you resolve this?
2. What actions, processes or systems are needed to deal with similar situations in future?
3. Have you any recommendations - for service users, for research funders, for researchers, for public involvement leads, for anyone else - to develop good practice in this area?

It was interesting to note that on a show of hands, many of the organisations represented at the session had yet to develop policies or procedures to respond to 'complaints' about public involvement in research. Delegates at the session were invited to contact Philippa Yeeles at the INVOLVE Coordinating Centre if this was an area of continued interest to them.

5. Conclusions

This was the largest INVOLVE conference yet, involving 438 delegates, with a wide range of presentations and posters by user-researchers, university researchers, NIHR staff, the voluntary sector, service users and the public. There was not only an increase in examples of involvement in research, but also a growing number of organisations and structures to support and facilitate involvement – this is encouraging as it shows the extent to which involvement is becoming embedded within research.

Whilst the conference remains a ‘safe place’ for new comers to research where the longstanding issues such as who best to involve and how to pay them for their work continue to be discussed, the debate has also moved on, to one of impact on research and on health and social care. Conference delegates discussed and debated how best these impacts can be facilitated, measured and reported.

Lastly, whilst there will be challenges over the coming years, this conference highlighted the opportunities ahead of us and delegates left encouraged and energised to continue to facilitate and research patient and public involvement in research.

Further information

The full conference programme and abstracts of the presentations can be downloaded from www.invo.org.uk/conference.asp

More information on INVOLVE is available from the website at www.invo.org.uk

INVOLVE

Promoting public involvement
in NHS, public health and
social care research

INVOLVE is a national advisory body that is funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development.

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