



Trine B. Haugen (born 1955) is Professor of Biomedicine and Vice-Dean for Research and Development at the Faculty of Health Sciences, Oslo and Akershus University College of Applied Sciences. She is Medical Editor of the Journal of the Norwegian Medical Association and member of the Research Committee at Oslo University Hospital.

Photo Thea Leivestad

Users should have influence, including in research.

But will such universal participation really serve its purpose, and is this participation effectively facilitated?

User participation in research – real influence?

User participation is no longer restricted to the recruitment of test persons to be included in research projects. The Report to the Storting *Good quality – safe services* (1) says: «When users are included throughout the research process, this research will reflect the users' needs and viewpoints to a greater extent, and enhance the certainty that new knowledge that will be of benefit to the health and care services will be produced. There is a need to facilitate increased user involvement at all stages of the research process.»

What is happening in Norwegian healthcare services to fulfil this need? In some research projects, user representatives are included in the project group and on the list of authors (2, 3). At a conference on user participation in research, arranged by the Norwegian Knowledge Centre for the Health Services and the Research Council of Norway last year (4), it became clear that the Ministry of Health and Care Services, the health enterprises and the universities all wish to reinforce user participation. The ministry argued that those who fund research activities should give added weight to applications that include plans for such participation. The Research Council of Norway has heeded this recommendation. Its forthcoming programme *Practice-oriented R&D in the health, welfare and care sectors* will include special requirements for user participation in projects (5), similar to the requirements imposed on applications to the programme *Practice-oriented R&D in the health and welfare services* (6). Imposing an absolute requirement for user participation could generate a risk that good projects that fail to include users will be left without funding.

The Report to the Storting (1) further says that: «Users should be included in advisory boards and committees to ensure real influence.» If this means that users should participate at all levels, we may ask whether this is appropriate. A quick glance at the composition of the research committees in the health enterprises shows that user representatives have been included in many of them, for example in the research committee at Oslo University Hospital (7). Other health enterprises, such as Helgeland Hospital, which undertake few research activities, have chosen «provision of information to, and communication with, the enterprise's committee of users on a regular basis» as an alternative (8).

The mandate for the research committee at Oslo University Hospital (9) states that its key functions include providing advice in matters of research policy and research organisation, helping ensure that the research is of high international quality, recommending distribution of funding and facilitating collaborative relationships. This requires good knowledge of research strategy and international research. The items in the mandate stating that the research conducted should uphold high ethical standards and that the committee should collaborate with other committees at the health enterprise are a different matter. Here, the voice of the users deserves to be heard.

Looking at the issues discussed by the research committee at Oslo University Hospital after user participation had been introduced,

one may ask whether the users can reasonably be expected to have an opinion on weighty matters such as new programmes, action plans, research infrastructure, development of improved career pathways etc. To form an opinion on all these issues, good knowledge of research strategy, application processes, evaluations and – not least – the terminology and abbreviations used at Oslo University Hospital/the University of Oslo. Most likely, the deliberations proceed no differently from the way they did before user participation was introduced, and facilitating the meetings to cater to the users as well as to the agenda is no simple matter. With thirteen professors and one user representative around the table, complying with the item in the hospital's strategy for user participation can scarcely be easy: «Users should be provided with an opportunity to contribute their user experience in research processes wherever this is relevant» (10). To ensure that the users have real influence – and thus provide an added value to the committee – inviting them to meetings is not alone sufficient.

We may question whether university hospital research committees are the best forum for drawing on the users' resources and experience. An alternative that might be more conducive to elucidating the users' perspective could be separate committee meetings with a prioritised list of topics and several user representatives attending. It could be worth noting a specification in the Report to the Storting: «The most important aspect, however, is to include users in the development of services on which they have viewpoints and from which they have experience» (1). Achieving this will require development of arenas where the users can promote their viewpoints.

References

1. Meld.St. nr. 10 [2012–2013]. God kvalitet – trygge tjenester. Kvalitet og pasient-sikkerhet i helse- og omsorgstjenesten. www.regjeringen.no/nb/dep/hod/dok/regpubl/stmeld/2012-2013/meld-st-10-20122013/4/8.html?id=709069 [17.6.2013].
2. Kjekken I, Aanerud GJ, Eriksson LR et al. «Så bruk oss da!» Organisering av og erfaringer fra samarbeid med brukere i fagutvikling og forskning. *Ergoterapeuten* 2013; 1: 26–31.
3. Kvien TK, Mowinckel P, Heiberg T et al. Performance of health status measures with a pen based personal digital assistant. *Ann Rheum Dis* 2005; 64: 1480–4.
4. Økt brukermedvirkning, bedre forskning! www.kunnskapscenteret.no/publikasjoner/16899.cms [17.6.2013].
5. Store satsinger: Norske forskningsprioriteringer i 2014. www.forskningsradet.no/no/Seksjon/Seksjonsside/1253981124430?lang=no [17.6.2013].
6. Praksisrettet FoU for helse- og velferdstjenestene. www.forskningsradet.no/no/Utlysning/PRAKSISVEL/1253978432105/p1173268235938?visAktive=false [17.6.2013].
7. Forskningsutvalget ved Oslo universitetssykehus. <http://ous-research.no/fu/> [17.6.2013].
8. Forskningsstrategi i Helgelandssykehuset perioden 2012–2015. www.helse-nord.no/getfile.php/Helgelandssykehuset%20internett/Styresaker/Styresak_12_2012_%20forsknstrategi_HSYK.pdf [17.6.2013].
9. Forskningsutvalget ved Oslo universitetssykehus. Mandat. <http://www.ous-research.no/cms/cms/view.php?base=radium&cat=fu/Mandat&aid=9758> [17.6.2013].
10. Strategi for brukermedvirkning 2013–2018. www.oslo-universitetssykehus.no/aktuelt/nyheter/Sider/strategi-for-brukermedvirkning.aspx [17.6.2013].