

Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <http://orca.cf.ac.uk/117315/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Noble, Simon 2018. Patient relevant bleeding complications; it's bleeding complicated. *Thrombosis Research* 172 , pp. 179-180. 10.1016/j.thromres.2018.10.032 file

Publishers page: <http://dx.doi.org/10.1016/j.thromres.2018.10.032>
<<http://dx.doi.org/10.1016/j.thromres.2018.10.032>>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Patient engagement in research: Are we really worse than orthopaedics?

Simon Noble Marie Curie Palliative Care Research Centre, 1st Floor, Neuadd Meirionydd,
Cardiff University, Heath Park Campus, CF14 4YS

The role of the patient is no longer purely that of a passive recipient of care. It is now commonplace for doctors to engage patients in their own care and treatment choices and many health services have developed initiatives encouraging patient involvement in the design, planning and delivery of healthcare. Furthermore, a growing body of evidence suggests that patients who are more actively involved in their health care experience better health outcomes and incur lower costs to the system. The terms “patient engagement” and “patient and public involvement” (PPI) are often used interchangeably even though they are not the same. Patient engagement is the process by which patients participate in the meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Within this umbrella term, PPI focuses on research being carried out with members of the public rather than just to or about them. This will include includes working with research funders to prioritise research, offering advice as members of a project steering group, developing research materials and even undertaking interviews with research participants.

The positive progress that has been seen in the uptake and acceptance of patient engagement within healthcare delivery and policymaking has not been realized, to the same degree, within healthcare research. This is unlikely to be because patient engagement in research is a new concept; on the contrary, it has been active within specialties, such as psychiatry, for decades.

Primary care research in particular has established patient engagement within its research programs such that it is custom and practice within this academic discipline. A quick literature review using the terms “patient-engagement” “primary care” and “research” will retrieve an initial return of over 5000 papers. Substituting the term “primary care” for “psychiatry”, “cardiology”, “orthopaedics”, “nephrology” or “thrombosis” yields returns of 1500, 242, 110, 124 and 42 respectively. Granted, such a “quick and dirty” literature search has a myriad of limitations and one needs to consider the results with caution. However, when patient engagement appears to be more active in orthopaedic research than thrombosis we should at least sit up and take notice.

The easiest response would be to dismiss these results for all the flaws such a limited literature search brings with it. But please indulge me for one moment and consider these questions:

- What level of patient engagement do you have in your current research projects?
- To what extent have you engaged with patient partners or organizations in progressing your research portfolio or grant applications?
- How often do you use patient reported outcome measures (PROMs) in your research and what weight do you place on them compared with other outcome measures?
- When did you last read a research paper involving direct patient engagement in a thrombosis journal?

Some of us will reassure ourselves that we do indeed engage with PPI; after all we always have patient representatives on our trial steering committees (TSCs) but are patient partners able to contribute to the research agenda in this setting or do they feel overwhelmed by the strong personalities and medical jargon? Regrettably, I feel we have a long way to go before it becomes commonplace for all TSCs to run in a way that empowers patient partners to contribute in a meaningful way more than tokenism. We also take comfort in the fact we set aside some money in our grant applications to measure quality of life (QoL), infact we are often told it may increase our chances of funding. We don't quite understand what the QoL data means or how it applies to patients but, hey, we can worry about that once the main paper is published.

I suspect I am being unfair; it is easy to criticize a specialty for its degree of PPI without understanding the reasons for it. It is no surprise that psychiatry and primary care have broad PPI in research since much of their research is direct patient facing and will often involve evaluation of concepts, events, behaviors, or feeling. Much of our research will be born in the laboratories long before making its way to phase 3 trials or becoming being embedded in clinical practice. It is through strong epidemiological analysis that we have been able to influence healthcare policy in areas such as thromboprophylaxis. In these types of research environments, the patient may seem a million miles away and any value that PPI may offer unclear. However, this need not excuse absence of patient engagement; for example, all research projects can include dissemination

plans for the general public, the funding bodies and relevant patient groups. In some barriers to patient engagement becomes a circular argument since we are unlikely to see the benefits unless we engage with it at all stages of research.

In this issue of *Thrombosis Research*, Lisa Duffet has produced a clear accurate and comprehensive overview of patient engagement in thrombosis research. Covering the opportunities for patient engagement from preconception through to study design, conduct, analysis and ultimately dissemination she outlines how patient engagement can offer real value to preclinical and clinical research rather than be considered a fashion which researchers may feel pressured to engage with. She outlines the different levels of engagement that can be considered and provides evidence of the impact of such patient in research. Finally, she outlines specific areas within thrombosis research where patient engagement has impacted on the research development of outcomes. Such an example is the ALICAT study: a mixed methods evaluation of the feasibility of recruiting patients to a study about anticoagulation beyond six months in VTE patients with ongoing active cancer. Whilst studies such as LONGHEVA and the second randomization of SELECT-D have demonstrated how difficult it is to recruit to such trials, they offer little explanation for why this may be so. Through direct patient engagement, researchers identified that people who had experience cancer associated thrombosis would have ongoing fixed beliefs and fears around their thrombotic disease and anticoagulation. As such they did not want to be randomized into an arm of a study, which was contrary to what they wanted to receive. Through this approach, clinical trials have used patient engagement to develop study interventions. Duffet's eminent yet readable overview she gives a roadmap for how research active clinicians and primary researchers from bench to bedside can engage in PPI in a way that adds true value to the research and overall patient care. It should be considered core reading for all academics, particularly those embarking on clinical research in the field of thrombosis and haemostasis.

One would hope, such a paper might herald a new era in thrombosis research where meaningful patient engagement becomes an integral part of our portfolios. Just by publishing this article, the editors have demonstrated they are receptive to research, which has patient engagement integral to its operational policies. This does not merely infer an openness to publish qualitative and quality of life research but rather an editorial policy, which recognizes the value of research that has occurred in partnership with the patients and the public. One might even hope that all academic thrombosis journals become receptive to the value of patient engagement in research and follow where *Thrombosis Research* has lead.

Is such a hope too unrealistic? Possibly, but 2016 has already been a pretty strange year and nothing would surprise me now.