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**Editorial**

**Involving the right people in diabetes research**

In the bad old days, research was often done *to* people without adequate information, with the agenda being driven by the researcher. Thankfully, those days are past and there has been an increasing recognition of the need to involve the public and patients in medical research. As well as being a fundamental democratic principle that people, who are affected by research, have a right to have a say in what and how research is undertaken, patient and public involvement improve the quality of research by making studies more accessible and acceptable while ensuring that research outcomes are important and relevant. The shared decision-making aligns research priorities better to the needs of society and in the end, all benefit. As Dame Sally Davies, the UK’s Chief Medical Officer, wrote, “No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”

In this issue, Finer *et al.* publish a prime example of how people with diabetes can work with healthcare professionals and researchers to shape the future research agenda (1). Following a previously successful exercise for Type 1 diabetes, Diabetes UK and the James Lind Alliance Priority Setting Partnership undertook a four-step process to determine the “top 10 research priorities” in Type 2 diabetes. 70,000 people with type 2 diabetes, their carers and healthcare professionals were contacted to complete a questionnaire and over 2,500 people from a diverse background responded with in excess of 8,000 uncertainties in Type 2 diabetes identified. These were distilled into 114 questions, which were distributed to more than 1500 people for the second survey. In response, the number was whittled down to 24 questions before the final “top 10” were selected. These included questions on prevention, cure and reversing diabetes, identifying those at risk and self-management approaches. The top 10 should now set priorities for both researchers and funders. At Diabetic Medicine, our response has been to commission a series of review articles about these topics, which will start to appear over the next few months.

Diabetes UK has been funding research since 1935 and over the last 80 years has committed resources to both projects and researchers. These have yielded many high profile success stories including studies of the first prototype insulin pen and first handheld glucose meter. More recently, Diabetes UK has funded studies of insulin pumps and structured education. It has also supported research into the prevention of complications, including the UK Prospective Diabetes Study, and indeed diabetes itself. I remember listening to Richard Lane OBE, former President of Diabetes UK and now Ambassador, describing to Diabetes UK groups how he is a living example of how Diabetes UK-funded research makes a difference to people’s lives after he became one of the first people in the UK to receive an islet cell transplant (<https://www.diabetes.org.uk/Your-stories/Type-1/Thank-you-is-inadequate-for-this-revolutionary-treatment>). Richard knew the value of communicating success stories and perhaps Diabetes UK has not “blown its trumpet” as loudly as it should. However, there is a recognition within the charity of the importance of evaluating and sharing the impact of its research. Robertson and Burns have started this dialogue in the first of many commentaries on Diabetes UK research emphasizing its key achievements.

Both of these papers show how when the right people get together, research can move in the right direction. Khunti and Seidu, however, discuss how challenges remain by highlighting the paucity of primary care diabetes research despite this being the place where most diabetes consultations happen. The increasing move towards primary care diabetes has not been mirrored by an increase in research in this setting. Over the last 50 years, research skills have developed substantially and there are ever more sophisticated databases to inform research. Despite these opportunities, primary care diabetes research only makes up 2.2% of all diabetes research output and if we are to make the best progress, we need to tap into this resource more effectively.

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References

1. Finer et al. Setting the top 10 research priorities to improve the health of people with Type 2 diabetes: a Diabetes UK–James Lind Alliance Priority Setting Partnership. DME13613
2. Robertson and Burns. Funding research to change lives: exploring the impact of Diabetes UK research. DME13643
3. Khunti and Seidu. Diabetes Research in Primary Care: Fiction, Reality or Essential? DME13638