

Individualised variable-interval risk-based screening in diabetic retinopathy: the ISDR research programme and RCT of safety, cost effectiveness and patient experience.

Supplementary material 1 Stages of PPI involvement in ISDR

Year	No Meetings	Work conducted	Outcome
2013	3	- <i>Setting the context</i> - Developing appropriate information and discussing DR, risk factors for DR, the LDESP, disease progression and grading, and the epidemiology within Liverpool.	Our group suggested that a 5% threshold would be appropriate, but in conjunction with the statistical team, finally agreed on a 2.5% level, described further in <i>WP C</i> .
2014	2	- <i>RCT</i> - Discussed variable screening intervals and the current scientific and medical knowledge about 6, 12 and 24 month screening intervals, the related costs of DR, not just financial but also related morbidity and mortality rates, and the concept of risk and setting the risk threshold for the RCT.	
2015	3	- Involved in supporting consent process for RCT - Discussions about non-attendance - Meetings with health economics (WP D) team regarding projected costs for variable screening and proposed ways for cost-savings to be re-distributed	- Suggestions for improvement translated in increased rates - Views expressed regarding re-distribution of cost-savings towards non-attenders.
2016	4	- Meetings with cohort study team - Meeting with director of LDESP	- Development of four patient-centred outcomes (STDR, treatment, visual impairment and health) - Fed into discussions on attendance rates and uptake of specific groups in LDESP
2017	2	- Further discussions with health economics team - Discussions on the work of WP F	Helped conceptualising the analysis and reporting of results.
2018	4	- Discuss plans for end of the RCT: advocated for an extension of the individualised arm to the NSC and the NIHR - Meeting with the National Director for Patients, Carers and Public of the NIHR - Involved in discussions on how to incorporate their expertise in the post programme planning. - Reviewing of the qualitative manuscripts	- Discussed options for the transition of ISDR RCT participants after the end of the RCT. - Presented the group's concerns about the gaps between PPI and the application of research outputs into practice.
2019	1	Prepared for the ISDR dissemination event	ISDR PPI panel discussion in ISDR dissemination event
Total	19		

DR, diabetic retinopathy; LDESP, Liverpool Diabetic Eye Screening Programme; RCT, randomised controlled trial; STDR, sight threatening diabetic retinopathy; NSC, National Screening Committee; NIHR, National Institute for Health Research; PPI, Patient and Public Involvement.