

Using the PE Quality Guidance to develop a national diabetes PROM intervention for standard care

made
with
patients

Description: Co-creation of a Patient reported outcomes measurement for diabetes with patients and caregivers

PEQG: Used the guidance to augment the quality of engagement with patients during the entire process



- 1 Patients were involved in defining shared aims and purpose
Unique needs and hopes of Patients participants were established
- 2 Patients were involved to identify how to secure RESPECT and INCLUSIVENESS of the UI process
- 3 Purposeful analytical recruitment of patient partners and large-scale patient surveys were used to ensure representativeness
- 4 Every activity involved clear lay explanation of background, aims, practicalities, and the specific roles of participants
- 5 Individual talks with each patient with diabetes, assessing needs. Pre-read provided with home exercise, agendas focus on PwD perspective and role
- 6 Ambition with and outcomes of user involvement were disseminated at the national, regional and local level to all key stakeholders for awareness and legitimacy
- 7 A user panel with patients dedicated to the project meets regularly to support continuity and large-scale implementation of intervention

Impact: Application of the PE Quality Criteria facilitated development and implementation of practical solutions to unmet needs identified by Patients with diabetes through effective User involvement

Lessons learned: All 7 Quality Criteria were found relevant from outset. Evaluations (surveys/interviews) found patients were positive towards process and outcomes. Project responsiveness to patient input and diversity of PwD were noted as important features. Area for improvement: Consistent use of lay language and avoidance of difficult acronyms