Annex 1. Recommended ways to include patient/user group engagement in CPRD research studies

Type of research	Purpose	Potential Patient/User Group Engagement
Measure the frequency of disease e.g., What proportion of the population have a new diagnosis of T2DM?	• Understand trends in disease • Assess unmet need • Inform health care planning	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • Publication/ communication of findings via patient organisation, social media, where planned.
How clinicians prescribe/patients use medication e.g., How many patients with T2DM are prescribed metformin, two therapies or insulin?	• Assess uptake of existing or new medication • Understand prescribing patterns and preferences • Gain insights on marker of disease severity • Quantify medication adherence and compliance	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • Feedback from patient groups about reasons for lack of medication adherence and compliance, if needed by the research or reported in the literature. • Publication/ communication of findings via patient organisation, social media, where planned.
Describe outcomes of ill-health e.g., Is the risk of heart disease among patients with T2DM higher than among non-diabetics?	• Understand the risk factors for diseases among different groups • Understand the magnitude of the risk of ill-health	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • Interpretation of results and dissemination of findings, where indicated.
Compare medicine effectiveness e.g., Is treatment with metformin more effective than glipizide in controlling blood sugars?	• Understand whether some treatments or combinations are more effectiveness than another • Understand whether different treatments are more effective in some patients than others	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • Interpretation of results and dissemination of findings, where indicated.
Drug and vaccine safety e.g., What are the major side effects of metformin? Are these already reported in the clinical trials or are these new effects. Are there more side effects in one class of drug more than another?	• Monitor existing drug safety issues once the drug is on the market • Identify new drug safety issues after the drug is on the market • Inform drug safety management plans	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • Involvement in the design, interpretation of results and dissemination of findings, where indicated.

Type of research	Purpose	Potential Patient/User Group Engagement
Assess clinical/regulatory guidance e.g., Do clinicians follow clinical guidelines when prescribing medication for T2DM?	• Assess whether patients meet National Institute of Care Excellence or other treatment guidelines criteria for receiving a particular treatment	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • May be involved in the design, interpretation of results and dissemination of findings, where indicated.
Studies on diagnostic/ clinical/treatment pathway e.g., What clinical pathways do patients with T2DM take to get a diabetes diagnosis.	• Understand how patients use the health service for diagnosis and management of their condition	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • Study conceptualisation and/or design e.g., provide insights on real world experience of the health services for exploration in the research or information drawn from published studies, where needed • Interpretation of results and dissemination of findings, where indicated
Methodological studies e.g., Can we predict who will develop T2DM in 10 years' time? Is method X to control for selection bias in T2DM treatment effectiveness studies more robust than Y?	• Understand the risk factors for diseases among different groups • Derive disease risk scores • Estimate treatment effectiveness using different methods	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • Publication/ communication of findings via patient organisation, social media, where planned.
Evaluate national health policy or programmes e.g., Has the NHS health check program reduced risk factors for T2DM?	• Understand whether the risk profile of patients who had a health check year on year is better than those who didn't have a health check.	• Communicate the public health problem and intended benefits of the research e.g., by reviewing the lay summary of the proposed research. • May be involved in the design, interpretation of results and dissemination of findings, where indicated