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| **Health Research Authority Permission** | | *Ethical permission and HRA permissions are in place for this study*  *Primary Care organisations should ask for a copy of any relevant permissions at the time of confirming their future involvement in the study*. *GDPR compliance is mandatory in order to receive CRN support.* |
| **Study Overview** | This is a multicentre, UK-based, observational study that aims to establish the feasibility of recruiting to a digital Patient Reported Outcomes Measures (PROMs) study via participant self-identification or contact from the primary care research network. It also explores the feasibility of linking the participants PROMS responses to regional and national NHS data sets.  We can use questionnaires to help us understand how a patient feels about their quality of life (QOL) and experiences of care. These surveys are called Patient-Reported Outcome Measures (PROMS). PROMS have been used in research to understand patients' quality of life. However, more needs to be done to understand the quality of life for patients in the long-term following a diagnosis of cancer.  As many patients are discharged from secondary care 5 years after diagnosis and treatment for cancer we need to find ways to identify and engage these patients to understand the long term consequences of cancer and its treatment. To do this, we need to understand how to engage participants in this type of research so that we can deliver high volumes of PROMS responses.  We also do not know what services patients use in the community to help them manage the long-term effects of their cancer or its treatment with the aim of improving their quality of life. This study will collect service use and can feedback that data at local and regional levels to support service design and delivery.  The study explores both a novel methodology but also explores which PROMS are preferred by the participants and how we can keep the amount of time and effort needed to complete the questionnaires as low as possible.  All patients over the age of 16 who have had any type of cancer in the past can take part. Patients will access the survey at a time that suits them using a digital link. They can complete the survey once or if they choose, a second time 12 months later. | |
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| **Documents Pack** | https://drive.google.com/drive/folders/10F0FlKbTHEW4rL2vxE71PN66CZvKcO-a | |
| **Study Aims & Outcome** | We aim to understand more about the long-term outcomes and service use of patients living with and beyond a diagnosis of cancer  The main outcomes are:   * Recruiting cancer patients and linking their data to cancer registries, * Communicating with patients and understanding the most efficient and preferred PROMs questionnaires, * Analysing, linking PROMs data, and following up patients | |
| **Chief Investigator(s)** | Dr Matt Williams | |
| **Site Type** | PIC | |
| **Recruitment Start Date** | 01/12/2023 | |
| **Recruitment End Date** | 01/09/2025 | |
| **Target** | 1000 | |

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| **Participant Criteria** | |
| **Inclusion Criteria** | 1. Anyone over the age of 16 who has been diagnosed (receiving treatment is not an inclusion criteria although we expect as this is a long-term survivorship study all participants will have received treatment) for any type of cancer in the past (> 12 months) can participate.  2. Participants who self-identify as having previously (time unlimited) received a diagnosis of cancer, based on histological, radiological, or clinical grounds (primary and/or metastatic cancer). Current treatment is not a barrier to participation, but the emphasis is on patients who have completed treatment.  Participants need to be able to access the secure online platform, using a mobile device or computer.  3. Have capacity and be able to provide informed consent via the online platform.  4. To be able to understand, read and write English, with or without support from a trusted individual e.g., friends, family, carer. |
| **Exclusion Criteria** | 1. Participants recently diagnosed with cancer (less than 12 months ago).  2. Participants unable to access secure online platforms.  3. Participants who do not have sufficiently good understanding of written English to complete the PROMs and are unable to be supported by a trusted individual to complete the questionnaire.  4. Participants lacking capacity and unable to give informed consent. |

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| **Practice Involvement** | |
| **GP Practice** | * Complete provided OID agreement * Run provided database search and identify potential participants. * Send out text invites to potentially eligible participants. * Inform LCRN and study team once SMS invites have been sent out by confirming:  1. Date SMS invites sent out 2. Number of SMS invites sent out. |

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| **Payments** *(where applicable)* | |
| **Service Support Costs**  *paid by CRN* | Database search: Suggested payment is £26 for 60 mins admin time (as per SoECAT) |

**To register interest in this study or if you have any queries, please contact:** [**lnw.primarycare@nihr.ac.uk**](mailto:lnw.primarycare@nihr.ac.uk)