

NCRI Bladder and Renal Group Priorities 2023 – 2026: Penile Study Group



NCRI Partners

NCRI is a UK-wide partnership between research funders working together to maximise the value and benefits of cancer research for the benefit of patients and the public. A key strength of NCRI is our broad membership with representation across both charity and government funders as well as across all four nations in the United Kingdom.



Contents

Introduction	4
NCRI Bladder and Renal Group structure at a glance.....	6
NCRI Penile Study Group strategic priorities	7
Strategic area 1: Audit.....	7
Strategic area 2: Diagnosis, cancer pathway and survivorship.....	7
Strategic area 3: HPV	8
Next Steps.....	9
Appendix A	10
NCRI Penile Group priority setting process	10
Appendix B	11
NCRI Penile Study Group strategy session 2022.....	11
Appendix C	12
Strategy sessions contributors.....	12

Introduction

The NCRI Groups bring the cancer research community together to develop practice-changing research, from basic to clinical research and across all cancer types, supporting NCRI's strategy. The NCRI Bladder and Renal Group is a multi-disciplinary community of researchers and Patient Advocates focused on developing research to improve outcomes for bladder and renal cancer patients.

Each NCRI Group engages in a prioritisation process to identify the priority areas in its area of research (Appendix A). This process dictates the work of the group as well as providing an assessment of the state of research for the wider research community.

The NCRI Bladder and Renal Group has identified its research priorities working with members of the research community, NCRI Partners and other funders. Within the Bladder and Renal Group is the Penile Study Group. Study groups are permanent groups that have an overarching remit to deliver a number of strategic priority areas in their respective disease or cross cutting areas. An overview of the NCRI Bladder and Renal Group structure can be found on page 6.

There are multiple areas the NCRI Penile Group has identified as priorities, an overview can be found below with full details on pages 7 onwards. The Penile Study Group will work to deliver all priorities identified through concurrent projects.

Three key themes emerged during the strategy setting process for the Bladder & Renal Group – and are equally relevant to the Penile Study Group. Each of these will form part of each working group's considerations when addressing their priority:

- **Standardisation of sample acquisition and storage across all sites and studies**
 Key to the success of the priorities outlined in this document is the standardisation of tissue and liquid sample collection for use in future research. More basic research to understand penile cancer is needed and so a national system to collect material and evaluate different biomarkers in parallel, for example, would aid research across the board. Related to this is the need for standardisation of clinical trials in order to facilitate the delivery of studies that will work at every hospital in the UK. Considerations and plans to address these areas, for example the development of standard protocols, will be factored into the development of all trials resulting from the priorities outlined in this document.
- **Consideration of under-served populations**
 This is a cross-cutting consideration across all NCRI disease groups: the spectrum of clinical research participants rarely reflects the true spectrum of the population in clinical need. Indeed, there are some groups, for example the extreme elderly who have specific needs which may need specific solutions derived from specific research. Therefore, every effort must be made to consider minority and under-researched populations as we develop every new study.
- **Consideration of the effects of cancer and its treatment on quality of life**
 The consequences of penile cancers and their treatments on a patient's ability to live with and beyond cancer will be considered in all work of the group. When developing trials, for example, considerations of the effects of treatments on quality of life should be built into the project from inception, measuring these effects where appropriate. The group will also consider undertaking work into the services people need for symptom management and wellbeing when undergoing treatment and after its conclusion. This will likely be in collaboration with the Living With and Beyond Cancer (LWBC) Group.

The strategies of NCRI Groups will be refreshed every three years. In addition, the research landscape will continue to be routinely assessed by NCRI to ensure the most pressing questions in the research landscape are addressed over the course of this three-year strategy.



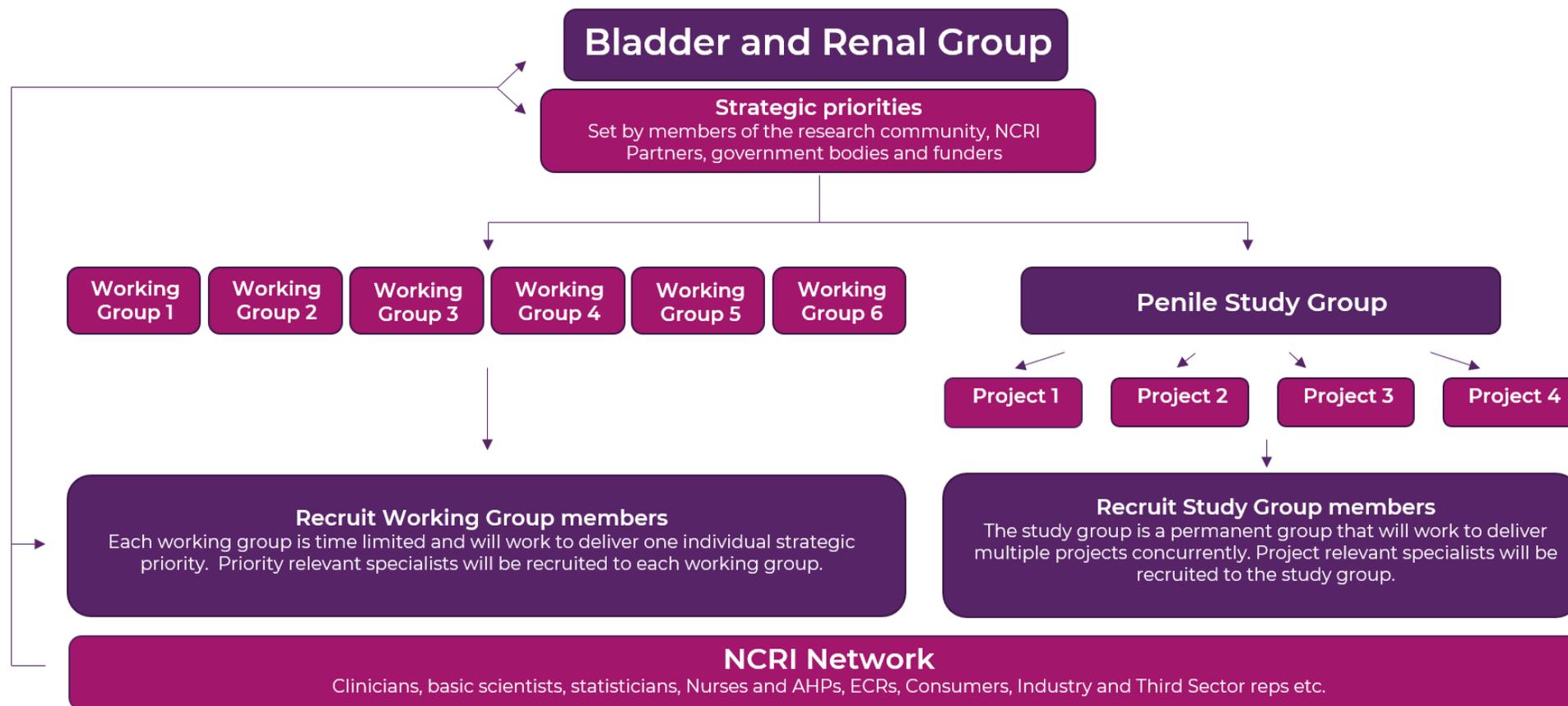
“Penile cancer services in the UK have come a long way in the last 20 years since centralisation, particularly with advances in penile preserving surgery and the introduction of dynamic inguinal sentinel lymph node sampling. However, many unmet needs remain. These are not only medical and significant further work is needed to support our patients emotional and relationship needs before, during and after treatment. The UK-NCRI penile cancer group have been working closely with patients and charities to identify these survivorship challenges and this forms a main focus of this strategy document.

Increasing awareness around penile cancer is also important and we hope that further efforts to do this will help to break down the stigma and taboo that still exists. Exciting opportunities also exist to support ongoing research into penile cancer, work with other NCRI groups on cross-cutting themes and to investigate the role of human papilloma virus (HPV) as a potential biomarker and therapeutic target in penile cancer. In reading this document, I hope that you will see the many exciting opportunities that exist for multidisciplinary research into penile cancer in the UK, which aim to improve the experiences and outcomes for our patients.”

Mr Ben Ayres, Chair of the NCRI Penile Group

Note: the wider NCRI Bladder & Renal Group priorities have been published separately and are available [here](#).

NCRI Bladder and Renal Group structure at a glance



Note: the wider NCRI Bladder & Renal Group priorities have been published separately and are available [here](#).

NCRI Penile Study Group strategic priorities

Strategy development involved identifying which of the proposals are already being worked on. The Penile Study Group will be focusing on new areas not currently being investigated.

Three themes have been identified as the NCRI Penile Study Group's Strategic Priorities. Discussions in the strategy meeting took place under these 3 headings. Two points are focused on survivorship and awareness with a strong patient angle and the other looking at HPV as a marker or other ways of looking at its role within penile cancer.

Patient advocate input into the discussions was key to identify the priorities. Patient advocates are driving much of the discussion in penile cancer research and researchers are working in collaboration with patients to move the field forwards.

Strategic area 1: Audit

Priority 1: Snapshot audit of penile cancer services

The first piece of work for the Penile Study Group to work on is the snapshot audit of services, documenting the issues that exist across the whole service pathway. This will lay the groundwork and drive future research questions. The audit would exist to understand how standardised available facilities in penile cancer centres are currently. It could do so through organisational survey / audit across penile cancer centres.

Strategic area 2: Diagnosis, cancer pathway and survivorship

A strength of the UK is the Two-Week Wait (2WW) referral pathway, but it is not being used as effectively as it could be in many areas. There is great interest in increasing 2WW referrals.

Priority 2: Early diagnosis, detection and treatment of early disease

Potential projects in this priority area include assessment and reach of educational programmes for the public and GPs; assessment of patient pathway / involving pharmacists giving information and advice to patients when distributing topical creams etc.

Priority 3: Raising awareness of penile cancer

Potential projects in this priority area include improving information given at time of HPV vaccine to boys and assessing the impact this has on awareness of penile cancer amongst boys and their parents.

Priority 4: Improve use of the two-week referral rule for penile cancer

Potential projects in this priority area include improving information given to patients by pharmacists upon dispensing topical creams; and targeted education programmes for GPs in areas with higher rates of penile cancer.

Priority 5: Improve referral and diagnosis

Potential projects in this priority include a GP led project designing and implementing a list of questions to ask upon description of symptoms of penile cancer during phone consultations.

Priority 6: Survivorship

This priority area focuses on assessing and addressing quality of life and unmet needs in penile cancer. Potential projects include assessment of the psychological impact of penile cancer, for example, avoidance of social interactions, impact on relationships, voiding difficulties and change in voiding, lymphoedema and impact on sexual function. A project could look at specific tools for addressing psychological and social impacts of Penile cancer.

Strategic area 3: HPV

This strategic area on HPV is a longer-term piece of work with a greater potential to unlock new treatments. The development of this area depends on how the landscape moves forward working with industry and vaccines. Recent scientific advances including HPV/P16 status being reported as a surrogate marker within pathology reporting, mean that now is the time to look at what may be possible regarding HPV.

There is a potential role in the treatment pathway for decision making and treatments (vaccine or otherwise or HPV pathway) using data coming out of inPACT trial.

Priority 7: Role of HPV status in treatment pathway and treatment decisions

Potential projects include investigating whether HPV negative patients need dose-escalation of adjuvant radiotherapy; determining if there is a role for HPV vaccines in PeIN and / or penile cancer management.

Priority 8: HPV pan-tumour study - potential to be cross-cutting across NCRI groups

This priority area focuses on diagnosis, staging and localised disease management.

Priority 9: Biomarkers and systemic disease management

This priority area involves investigating the role of HPV status as a biomarker. Potential projects include investigating whether we can determine markers of effectiveness of radiotherapy in terms of HPV status within the InPACT trail.

NCRI Cross-cutting priority

Identify barriers resulting in a lack of diversity in clinical trials and propose solutions to improve equality, diversity, and inclusion.

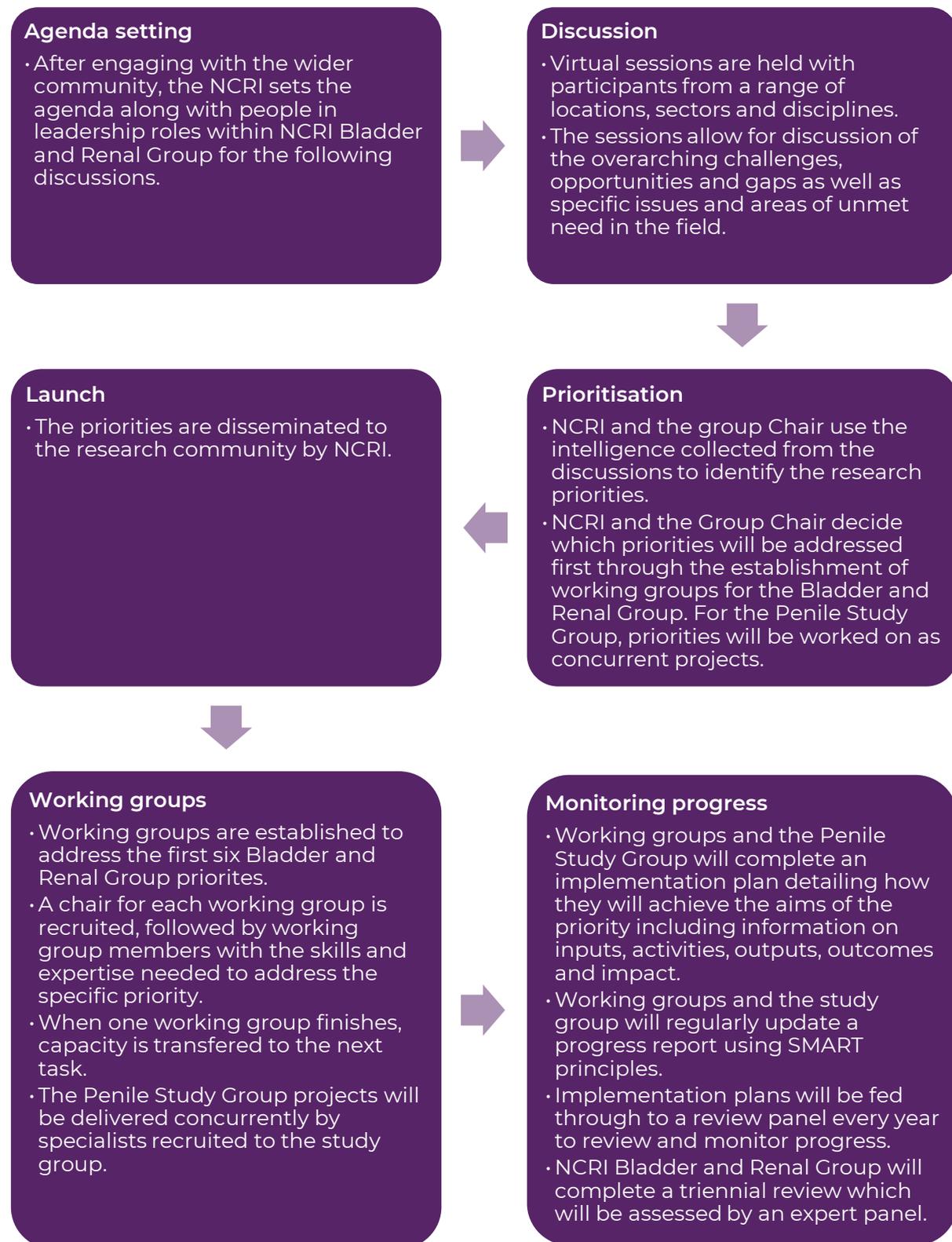
Barriers resulting in a lack of diversity in clinical trials across cancer types has been raised as an issue in many of NCRI's discussions with researchers. For this reason, this priority will be addressed collaboratively in a working group comprising experts from across NCRI Groups. This priority aims to establish the reasons behind a lack of diversity in clinical trials and provide solutions to increase participation of a diverse cohort of patients in future studies. A working group will address the common issues across the board, as well as identifying cancer-type specific barriers, and produce guidelines on the steps to take to improve the inclusion of patients from a range of backgrounds into clinical trials from their inception. More details on this working group will be decided in due course.

Next Steps

As a group of dedicated clinicians and patients, to manage and improve research and outcomes in penile cancer, the NCRI Penile Study Group will continue to work on these priorities with national and international partners.

Appendix A

NCRI Penile Group priority setting process



Appendix B

NCRI Penile Study Group strategy session 2022

The NCRI Penile Study Group held its strategy session in July 2022. Participants included NCRI Patient advocate Forum members, early career researchers and NCRI Partners. The introductory presentations allowed for discussion of the current landscape and the overarching challenges, opportunities, and gaps in research, whilst the subsequent breakout sessions gave the opportunity to exchange ideas on priorities areas of future research in this field, with each group involving researchers from wide ranging disciplines encouraging cross-cutting collaboration to meet the most pressing needs in research into penile cancers today.

Date: 15th July 2022

Chair: Prof. Vincent Khoo

Discussions:

- Diagnosis, staging and localised disease management
- Biomarkers and systemic disease management
- Patient pathway, education and survivorship

Appendix C

Strategy sessions contributors

Abbie Fearon (NCRI)
Alice Kidd (NCRI)
Amit Bahl
Anita Mitra
Arie Parnham
Ben Ayres
Carolyn Chan
David Wilkinson
Dominique Parslow
Duncan Summerton
E Lin
Eileen Nolan
Emma Hall
Fiona Bonas
Ian Dawkins
Jaymini Patel
John Osborne
Prof Vijay Sangar
Qiuyu Wang
Rachel Pearson
Stephanie Burnett
Stephen Sha
Steve Nicholson
Vincent Khoo

Report produced by:

Anna Fry, Programme Manager, NCRI
Emma Ross, Programme Coordinator, NCRI
Nicola Keat, Head of Groups, NCRI

National Cancer Research Institute
2 Redman Place,
London, E20 1JQ

T: +44 (0)20 3469 8798
info@ncri.org.uk