

Role Profile for Consumer Members of NCRI Cellular Molecular Pathology (CM-Path)

Pathologists are medical doctors who are critical members of the health care team, combining a scientist's understanding of what laboratory evidence suggests and a specialty physician's knowledge of medicine to determine the correct diagnosis. Pathologists are physicians, having studied at medical school, completed junior doctor foundation years of training and been through a subsequent five years of pathology specific training.

Overall, pathologists ensure laboratory quality so that diagnostic testing is safe and accurate. They are responsible for the diagnostic accuracy of every test. Often, they guide primary care and other doctors, determining the right test, at the right time, for the right patient.

Although patients may never meet the pathologist on their care team, they can be assured that these experts deliver quality and care are at every step.

Find out more about what a pathologist does in just one minute... <https://youtu.be/gtF82brtP1w>

On any given day, pathologists impact nearly all aspects of patient care, from diagnosing cancer to managing chronic diseases such as diabetes through accurate laboratory testing.

They diagnose all types of medical conditions:

- ✓ Diseases—by studying specimens such as polyps and biopsies
- ✓ Genetic disorders—by using molecular biology and genetics
- ✓ Skin diseases
- ✓ Nervous system diseases
- ✓ Diseases that affect blood cells
- ✓ Microbes that cause infections
- ✓ Fetal, infant, and childhood diseases

From surveys conducted by CM-Path we know that:

- Patients are often unclear on the role of pathology as a specialty and our ability to direct patients in their health care journey. CM-Path aims at creating a direct participation of patients to guide the programme through all changes in pathology to ultimately benefit patients.
- Similarly, pathologists are often unaware of the potential effect they can and should have on the changing face of medicine. They can accomplish collective goals and take an active stand in the evolution of health care.

The NCRI Cellular Molecular Pathology (CM-Path) initiative aims to improve diagnosis and treatment of cancer patients by breathing new life into academic cell and tissue-based pathology. It will provide strategic co-ordination of research training, basic and translational research opportunities and implementation of new approaches in pathology for faster innovation in cancer care.

The CM-Path initiative brings together a working group of experts from pathology and other disciplines to make advances in pathology research. The importance of pathology is increasingly being recognised in drug development and clinical research. CM-Path therefore aim to change the way pathologists engage with, conduct and are recognised for their work in clinical trials in the UK.

CM-Path was originally funded for five years. The group has been working for three years now, with year four beginning in June 2019.

For more information, please visit <https://cmpath.ncri.org.uk>.

Role Description – The Generic Consent Strategic Delivery Group

Role	Consumer member of the CM-Path Generic Consent Strategic Delivery Group
Duration	<p>The CM-Path initiative is currently funded until June 2021. If the project is completed before this time, then consumer members will have completed their role and will rotate off the programme.</p> <p>Appointments of consumer roles will be made subject to an annual performance review with the CM-Path Programme Manager and CM-Path Chair (to ensure that the aims and objectives are on track).</p>
Expenses	Travel expenses and other reasonable out of pocket expenses are reimbursed and members may claim an honorarium for agreed meetings. Members are subject to the NCRI expenses policy.

CM-Path require 2-3 consumers to help deliver a generic consent form for use in the NHS in the UK. CM-Path have a vision to create a generic consent form that can be used across the UK to ensure that patients and all staff involved in the collection and use of tissue know where they stand with regards to tissue being used for research. We would like the consumer input to be as follows;

- Assess the feasibility of having such a generic consent form with key organisations in government and healthcare
- attend workshops and group discussions to make this become a reality
- help us to lobby at the highest level of relevant and appropriate organisations for this change
- write the generic consent form to ensure that it is appropriate and understandable by patients.
- develop the form and see this through to regulatory approval.
- help with dissemination and monitoring of uptake of the consent form as well as developing impact assessments of this change.

Further information

All roles require:

- Attending and actively participating in CM-Path Group meetings (TC and face to face) and in the NCRI Consumer Forum meetings, as well as participating in CM-Path workshops/events with additional email and telephone correspondence outside of these meetings. Further detail is contained in the 'time commitment' section
- Contributing the views of patients/carers to the discussion at the meeting.
- Preparing for meetings by reading meeting papers
- Attending and providing appropriate regular feedback on consumer activity to the Consumer Forum within the agreed rules of confidentiality outlined by the Group Chair.

- Abiding by any requests for confidentiality and to declare any conflicts of interest if they arise.
- Identifying personal learning and development needs with the NCRI Consumer Lead; and participating in appropriate learning and development opportunities to address these needs as required, within available resources.
- Providing meeting reports on their involvement in activities or meetings relating to the NCRI Consumer Forum and CM-Path Chair as appropriate and required.
- Acting as ambassador for NCRI's cellular molecular pathology activities in the wider world.

Role Requirement

Members are required to have:

- Relevant experience of cancer services as a patient, carer or relative.
- An appreciation of the importance of pathology in cancer diagnosis and treatment.
- Knowledge and understanding of consumer perspectives, with an ability to research and raise a broader range of consumer perspectives beyond their own personal experience.
- The willingness to learn about the current pathology research landscape leading to inception of this initiative.
- Willingness and ability to familiarise with relevant research and medical language.
- Some roles may require specific knowledge or a willingness to learn and familiarise yourself with consent, biobanking, pathology requirements in clinical trials.
- Good communication skills with an ability to listen to others and constructively express one's own view from a consumer perspective.
- An ability to work effectively and constructively as part of a team within a group of professionals.
- An understanding of the relevance of consumer involvement in the work of the NCRI.
- Computer literacy and the willingness to monitor email accounts on a regular basis.

It is also desirable for members to have:

- Experience of participating in formal meetings and committees where there is a routine expectation for group members to prepare and comment upon meeting papers that may be complex.
- An understanding, and if possible, experience of the issues involved in both cancer and wider consumer networks and groups.
- Interest in keeping up to date with current pathology research issues.
- Ability to respond appropriately to challenging tasks, including distilling key information from meeting papers and other relevant documents.
- Experience with pathology/pathologists
- An experience with consent procedures, biobanking and clinical research
- An awareness of pathology and the issues facing the discipline

Training and Support

It is expected that you will be required to dial into monthly teleconferences (1 hr) and may be expected to join face to face meetings where appropriate to drive this project forward.

In addition, the Consumer Forum will meet two to three times per year. Members should attend Consumer Forum meetings regularly and as required provide an update on the work of CM-Path. Consumers are also encouraged to attend further NCRI events such as our 3-day conference, to be held on 2-4th November 2020.

A 2-day 'NCRI Consumer Training' training course in more general aspects of consumer involvement will also be arranged. Should you be appointed to this role you should be available to attend the training session (2020 dates tbc)

Attendance fees and expenses

Attendance and expenses fees will be paid in accordance with NCRI's current payment policy. Payments will be made without deduction of Income Tax although they are regarded as income for tax purposes. Individuals are responsible for declaring their income to HM Revenue and Customs.

People in receipt of state benefits and allowances are required to declare changes in their circumstances to their local Jobcentre Plus office. If you are concerned about the possible impact of accepting payment on your benefits and allowances, please contact your local Jobcentre Plus office and/or your local benefits advice agency.

More detailed information about the process of reclaiming expenses and honoraria will be provided to successful applicants.

Training and support

The NCRI Secretariat will provide an induction and also arrange ongoing support and mentoring, at an individual level, on issues relating to the work of CM-Path. The Secretariat can also provide briefings to help clarify specific issues in advance of meetings. Consumer members will be offered the support of a scientific mentor from the NCRI Executive. See more information on training available in the 'Time commitment' section above.

Declaration of interests

All Group members are required to declare if they have any interests that might be in conflict. A conflict of interest does not stop you from being a CM-Path Group member. However, it may mean that you cannot take part in some discussions or decisions made on projects/issues where you may have a conflict of interest. If in doubt you should seek advice in the first instance from the CM-Path programme manager. The [Nolan Principles](#) may provide useful guidance in this area.

Confidentiality

CM-Path Workstream members must not communicate any confidential information that they learn as a result of being a Workstream member. However, there may well be occasions on which Workstream members are specifically asked to share information within their own communities or seek the opinions and views of others. If you are unclear about whether or not information that you have access to is confidential, please seek clarification in the first instance from the CM-Path Team or the Workstream leads.

Further Information

If you would like any more information **before** making an application please visit www.ncri.org.uk, or contact Helen Pitman on 020 3469 8530; email helen.pitman@ncri.org.uk

Code of conduct

The NCRI's purpose is to improve health and quality of life by accelerating progress in cancer-related research, through collaboration. To help us achieve this, CM-Path Workstream members are asked to:

- Abide by the values highlighted in the NCRI strategy, by being collaborative, dynamic and determined, and acting with integrity, professionalism and intelligence
- Always act in the best interests of the charity and support NCRI's 4 key strategic aims, to:
 - Ensure a coordinated portfolio of research related to cancer
 - Seize opportunities and address challenges in research relevant to cancer
 - Continuously improve the quality and relevance of research related to cancer
 - Accelerate the translation of cancer-related research into practice

Application Process

If you are interested in applying, please click the following link to access the application form:
<https://www.ncri.org.uk/consumers/cm-path-membership/>

The deadline for *all* applications is **Wednesday 1st January 2020**