## Additional Information for AI Accelerator Grant Applicants: Understanding and Integrating Patient Perspectives

Ovarian Cancer Research Alliance (**OCRA**; USA), Ovarian Cancer Action (**OCA**; UK), Ovarian Cancer Canada (**OCC**; Canada) and the Ovarian Cancer Research Foundation (**OCRF**; Australia) have launched a \$1M (USD) international research grant program focused on harnessing AI to improve ovarian cancer outcomes. The following insights were collected by funding partners, from individuals with lived experience of ovarian cancer (as a patient or caregiver).

#### Who did we hear from?

**65** / individuals globally

Including women who have been diagnosed with ovarian cancer, previvors and family members / caregivers.



#### **Research priorities**

The following were consistently identified as top priorities for ovarian cancer research:



#### **Early detection**

Including reliable early detection tools or screening tests, biomarker research, and symptom awareness to support earlier clinical intervention.



#### **Better treatments**

Including more effective and less toxic options, targeted therapies, immunotherapy, alternatives to chemotherapy and personalised medicine.



#### Disease recurrence

Including what drives recurrence, methods to detect recurrence earlier, how to delay or prevent recurrence, and supportive care approaches for those living with recurrent or incurable disease.

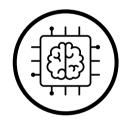


#### **Risk & prevention**

Including improved risk prediction for those with a family history or known genetic mutations and maximizing opportunities for ovarian cancer prevention.

## **Perspectives on Al**

OCA asked women affected by ovarian cancer for their thoughts on the use of Al in cancer research:



~75-80%

expressed positive or broadly supportive views

## Perceived benefits / promise of Al

- Accelerate progress
- Enable earlier diagnosis
- Make use of large / complex datasets
- · Reduce research costs / time
- Spot patterns that humans may miss
- · Identify new targets for treatment
- Analyse recurrence risk or treatment responses faster

#### Concerns / notes of caution

- Must not replace human care or clinical judgement
- Must be used ethically and transparently
- Patient data must be protected









Why PPI matters Patient and public involvement **(PPI)** makes research stronger, more relevant, and more impactful. By working with those directly affected by ovarian cancer, you can ensure that your proposed research addresses real-world patient needs, considers ethical concerns, and delivers meaningful outcomes. Embedding good quality PPI into your application could help improve your chances of success, not only of your application but of the research itself.

## **Embedding PPI into your research plan**

Each full proposal will be evaluated by independent scientific experts and global patient reviewers. Reviewers will expect:

- A well-defined PPI strategy with patient involvement at key stages.
- Plans for regular and ongoing engagement beyond a single meeting.
- A clear explanation of how your project aligns with patient-identified research priorities.
- A careful consideration of ethical concerns (e.g., AI bias, data privacy) with patient input. If patient data is used, follow national data protection regulations (e.g., GDPR in the UK/EU, HIPAA in the US, PIPEDA in Canada, OAIC guidelines in Australia).
- A budget that includes PPI activities (e.g., honoraria).

#### **Principles for meaningful PPI**



## Early and ongoing engagement

Involve patients from the start to help shape research questions, guide study methodology, and interpret and communicate findings.



#### Make it a partnership

PPI isn't just consultation, it's a mutually-beneficial collaboration. Define clear roles and modes of engagement and ensure patient voices are valued within your team.



#### Communicate clearly

Use plain language, make technical aspects accessible and keep patient partners informed of research progress.



#### Be inclusive & representative

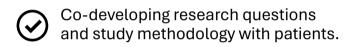
Where possible, engage a diverse group of patients to ensure AI models reflect real-world populations.

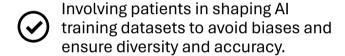


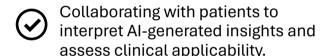
#### Recognize contributions

Compensate patient partners fairly and acknowledge their contributions and impact.

## **Examples of PPI in AI research**







Establishing advisory groups to review progress and guide decision-making at key project milestones.

Involving patients in the development and review of lay language materials, manuscripts and meeting abstracts.

# Need help connecting with patient partners?

**AUS -** Facilitates patient involvement in research. Contact jemma.gomularz@ocrf.com.au.

**CAN -** Connect with OCC's Patient Partners in Research team by contacting <u>jlawson@ovariancanada.org</u>.

**UK** - Contact <u>Research@ovarian.org.uk</u> to learn more.

**US** - Contact <u>grants@ocrahope.org</u> for information.