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# Summary

Since its founding in 2013, the Centre for Personalised Medicine (CPM) has grown into a successful communication and engagement platform for research into a broad range of personalised medicine topics. The aim of this document is to outline the vision and strategy of the CPM as it enters its second decade.

The CPM's **vision** is that effective personalised medicine should be available for all. Its **mission** is to be a trusted and collaborative partner, supporting the development of equitable and effective personalised medicine, identifying appropriate questions, facilitating constructive debate and developing solutions across disciplines and audiences.

The CPM will focus its efforts on a series of topics within six broad and overlapping themes, asking questions about how research in these areas can be successfully translated into effective means to personalise medicine and influence relevant policy:

- diagnosis and treatment,
- risk and prevention,
- evolving health system boundaries,
- issues of equity,
- issues of sustainability, and
- experiences of personalised medicine.

Looking ahead, the aim is to further broaden the horizons of the CPM through diversifying its funding portfolio, both through CPM-led applications as well as via broader alliances, partnerships and collaborations.



## Background

The CPM was founded as an innovative partnership between St Anne's College and the (then) Wellcome Trust Centre for Human Genetics at the University of Oxford. Its goal was to provide a focus for multidisciplinary collaboration, dissemination of knowledge, and facilitation of new research, relevant to a range of public, professional, academic and policy-influencing audiences.

Since 2013, the CPM has grown its portfolio of activities and expanded in size from one Director and one Administrator to a core team of currently nine people (Director,



Programme Co-ordinator, Administrative Officer and six Research Fellows) that run the day-to-day activities, supported by a Steering Group and an External Advisory Board.

The CPM is grateful to receive generous funding from the Dr Stanley Ho Medical Development Foundation (renewed funding in place until 2030), which together with the University of Oxford has supported the CPM since its launch.

### What does the CPM mean by personalised medicine?

Medicine has always been personalised to some extent: health professionals use available data about a patient to predict or diagnose ill-health and select appropriate interventions or treatments. Yet terms such as personalised medicine - or similar concepts such as precision, stratified, or P4 medicine (predictive, preventative, personalised and participatory) - have been increasingly used over the last two decades to describe attempts to integrate new or previously unused data insights into healthcare to make better individual predictions, treatments or interventions.

Many different data types can be used to personalise medicine and much attention has been given to how genomic data might be used. However, other data types, such as epigenomic, proteomic (or other-omic data), and data about socio-demographic factors or early life exposure, are equally important to consider in the personalisation of medicine for all.

We define 'personalised medicine' as any attempt to use insights from what we can measure about individuals to inform healthcare.



### Context

The last two decades have seen many notable successes in research into personalised medicine, with studies promising improved prediction, diagnosis and treatment in many different settings.

Many developments have been hailed as 'transformational' and 'revolutionary' and have attracted significant political and financial investment globally [1, 2], yet the implementation of research findings into clinical practice and policy has often been slower than anticipated [3]. Furthermore, optimism about the possible benefits can obscure some of the harms. For example, uncertainties about disease diagnosis, severity, or age of onset, are often amplified rather than reduced by increasingly sophisticated technology, and the clinical management of disease risk is often more problematic than the treatment of an overt disorder [4, 5]. Examples include uncertainties from false positive diagnoses of conditions [6-8] or findings of uncertain clinical significance that inevitably result from more granular data approaches [9]. Headline figures of increased relative risks often translate to modest absolute, or lifetime, risks, and attempts to predict phenotype from genotype may create rather than remove diagnostic 'odysseys' [10,11].

The CPM recognises that an important aspect of personalised medicine is that currently the costs and benefits are not equitably distributed globally. Research databases are often significantly skewed towards populations of European ancestry [12], leading to a poorer understanding of the clinical implications of data across underrepresented populations. Additionally, socioeconomic inequalities are widening, and personalised medicine initiatives may exacerbate this, as many populations that already experience worse health outcomes are often also underrepresented in research databases.

The environmental impact of personalised medicine projects may also widen health inequalities for less affluent countries [13,14]. Recognising, tackling, and learning from the uncertainties that personalised medicine presents is a significant role for the CPM. This includes facilitating honest conversations so that these issues can be navigated, helping to identify and agree appropriate trade-offs; and engaging with diverse stakeholders and policy makers.



# Vision, mission, priorities and methods

# **Our Vision**

is that effective personalised medicine should be available for all.



# Our Mission

is to be a trusted and collaborative partner, supporting the development of equitable and effective personalised medicine; identifying appropriate questions; facilitating constructive debate; and considering solutions across disciplines and audiences. This will be delivered across a wide range of approaches and activities.



# **Our Strategic Priorities**

are to deliver our mission through **three core priorities** with **three supporting methods** whilst continuing to seek creative ways of engaging relevant audiences, including: academics; charities; clinicians; industry; patient groups; policy makers; publics; and students.



# **Core Priorities**

### 1. Themes

Research and engagement efforts will focus on topics addressing one or more of the six themes (see Figure 1). The topics will be defined and reviewed annually according to set criteria (see Figure 2).

### 2. Partnerships

To maximise the impact of the CPM as a small organisation we will foster new internal and external partnership opportunities.

#### 3. Engagement

The CPM will continue to engage internationally, leveraging its position in Oxford to support this reach. Working with the Nuffield Department of Medicine's (NDM) overseas units will be a priority, as well as supporting the goals of the Dr Stanley Ho Medical Development Foundation.

## **Supporting Methods**

### A. Research

Facilitating the launch of new programmes and projects was one of the CPM's founding objectives. This will be expanded to include the direct development of research within the CPM and with partners.

### B. Debate

One of the CPM's key strengths is the quality and diversity of debate and engagement facilitated through its portfolio of events. This will remain a cornerstone of delivering our mission.

### C. Outputs

Events, discussions and research outputs will be shared widely and made available on our new website and other platforms.

# Strategic delivery I: Core Priorities

### 1. Themes

The CPM will focus its efforts on a defined set of topics within six broad themes (three pillar themes and three cross-cutting themes, see Figure 1). Topics within these themes will provide the focus for activities each year. These will be evaluated according to a set of selection and prioritisation criteria (see Figure 2).

#### Figure 1: Themes



#### **Pillar themes** (domains in which personalised medicine operates)

- **Diagnosis and treatment**: Personalised testing and therapies (e.g. genomic sequencing for cancer or rare disease diagnosis).
- **Risk and prevention**: Examining the methods and impacts of disease risk evaluation and prevention (e.g. newborn genome screening and polygenic risk scores).
- **Evolving health system boundaries**: Examining how routes into healthcare systems are changing (e.g. through direct-to-consumer testing and wearable devices).

# **Cross-cutting themes** (considerations relevant to all areas of personalised medicine)

• **Equity**: Exploring how personalised medicine approaches can be made equitable across diverse populations.

- **Sustainability**: Examining how personalised medicine approaches will impact economic and environmental sustainability of healthcare provision and how these impacts can be mitigated.
- **Experiences of personalised medicine**: Understanding the experiences of those affected by, or involved in, the process and outcomes of personalised medicine.

Figure 2: Topic selection and prioritisation framework



# 2. Partnerships

To maintain and deliver on the aspiration of this strategy, the CPM will leverage its existing relationships and expand its approach to both internal and external partnerships.

The partnership between St Anne's College and the Centre for Human Genetics (CHG) allows CHG to feed a range of **research** perspectives into the CPM, including those of the Director and research fellows' research groups, supporting the future development of personalised medicine. St Anne's College provides the **connectivity** to host events and activities. Together these provide networking opportunities as well as public and community engagement with research, with **reach** to the wider University. These interactions then provide **impact** to external stakeholders (see Figure 3).

The CPM will forge new collaborations with research programmes that fit with our strategic priorities, both within Oxford and further afield, and will continue to develop partnerships with like-minded organisations, for example, through joint meetings with the PHG Foundation at the University of Cambridge, or the British Society for Genomic Medicine.

The CPM will develop a new initiative of **affiliate membership**, providing a route to bring in people and organisations working in aligned areas where helpful to delivering its mission.

In this way the CPM will continue to expand and develop new types of partnerships to ensure a dynamic exchange where research and engagement activities co-create new understandings of the potential of personalised medicine.



#### Figure 3: Partnership framework

### 3. Engagement

The CPM's vision for effective personalised medicine to be available to all is deliberate in its breadth. Advances in healthcare do not impact just one country or population, nor do they impact them all equally. As a result, the CPM must focus on international engagement. This will include:

- Exploring international research and engagement opportunities both within existing CPM networks and through wider Oxford links, including the NDM Africa-Asia programmes and the Global Health Bioethics Network.
- Developing engagement efforts with Hong Kong, Macau and the wider Pearl River Delta region of China through the relationship with long-term funder the Dr Stanley Ho Medical Development Foundation. This will include:

- Providing content for the Foundation's knowledge exchange platform through live-streamed events, and through adding local language subtitles to lectures. The CPM will work closely with the Foundation to tailor its content to the needs of an international audience.
- Investigating opportunities for new international collaborations that allow insights into personalised medicine.



# Strategic delivery II: Methods

# A. Research

CPM research will be delivered both through partnerships with other research teams and through CPM funding applications. The CPM will aim to collaborate in large-scale applications to support recent calls by research funders to improve focus on public and participant engagement, dissemination and research impact.

## **B. Debate**

The CPM will facilitate high-quality debate around ways to personalise medicine, asking pertinent questions, and bringing diverse viewpoints together. This will be delivered through a portfolio of events that map to the prioritised themes and topics, which will include:

- **CPM Annual Lecture**: To be given by a high-profile speaker on a personalised medicine-related topic, aligned to the identified topics of the year and accessible to a lay audience.
- **Dr Stanley Ho Memorial Lecture**: To be given by a high-profile speaker with a more technical or scientific lens, but still accessible to a lay audience as well as more specialist one.
- Annual Research Showcase: To include talks by current CPM research fellows, Oxford University Personalised Medicine Society (OUPMS) members, students and researchers from a range of career stages.
- Events focussed on topics of current interest to the CPM: These are usually half- or one-day events featuring multiple speakers, and including workshops and debates. Examples include Genetics and insurance: Complexities in the genomic era, with the British Society of Genetic Medicine (BSGM), May 2024 [15]; Familial genomic information, with the PHG Foundation and BSGM, November 2023 [16]; and Opportunities and challenges for polygenic risk scores in healthcare with Cambridge Prisms, April 2023 [17].
- One-off events at St Anne's or CHG, given by either CPM fellows or their guests.

## C. Outputs

The portfolio of outputs will include:

- Journal articles from CPM research, and that developed in partnership with other research groups.
- Position papers / white papers on certain topics. [15] [16]
- Podcasts, blogs and vlogs to explore topics of relevance to CPM in depth [18-20].
- Videos of CPM talks and events [19].

• Video animations that explain core concepts in personalised medicine to lay audiences [21].

The CPM will feature all these **outputs** through the new website and regularly review their reach and impact to ensure the modes of engagement are appropriate.

We welcome enquiries or suggestions regarding this document.

You can contact us via the website <a href="https://cpm.ox.ac.uk">https://cpm.ox.ac.uk</a>





Laranya, aged 13 from Worksop College, Nottinghamshire Scarlett, aged 12 from Worksop College, Nottinghamshire Art competition winning entries 2024



#### Some of our podcasts and vlogs

# References

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[18] <u>https://cpm.ox.ac.uk/listen-to-our-podcasts/</u>

[19] <u>https://cpm.ox.ac.uk/blog-landing-page/</u>

[20] https://cpm.ox.ac.uk/watch-our-lectures-interviews/

[21] https://www.youtube.com/playlist?list=PLI2V44CoMrCqdiB-pPyEf7DoifGePYYeN

# **Appendix: Governance and structure**

We recognise that some structural changes may be required to accommodate the plans in the strategy. For example, expanding our direct research approach may require a new affiliate membership of the CPM via CHG rather than St Anne's and thus, different from the current research fellows who are contracted through St Anne's College. In this way the partnership between CHG and St Anne's will continue to expand the CPM's reach and capabilities supporting both research and engagement activities.





The Terms of Reference for both the Steering Group and External Advisory Board (EAB) were updated and approved by the Steering Group in March 2024. The responsibilities and composition of the groups can be summarised as follows.

## **Steering Group**

### Responsibilities

- Provide assurance to partner bodies (Centre for Human Genetics and St Anne's) and donors of the academic, financial, legal and reputational standing of the CPM.
- Provide strategic and operational direction, advice and support to facilitate the development of the CPM and maximise its impact.

- Have general oversight of the CPM, its management and activities, including appointments, academic activity, annual planning, budget and spending.
- Monitor and approve strategies for fundraising, income generation and financial outcomes, including reports on applications for outside research grants.
- Support the Director and Co-chairs to make best use of the EAB.

#### Composition

The Steering Group is co-chaired by representatives from St Anne's College and the Centre for Human Genetics, and the membership comprises representatives from other centres within the Nuffield Department of Medicine and other University departments.

## **External Advisory Board**

#### Responsibilities

- Provide advice and guidance on the strategic direction and role of the CPM.
- Promote and support the work of the CPM.
- Provide links between the CPM and major organisations in the fields of medical and scientific research, medical practice, medical education and to connect to public policy makers in the field of medicine worldwide.
- Assist in fundraising and income generation.

The remit of the EAB remit is to provide advice and guidance on strategy but also to provide a wider perspective on relevant issues as they arise. It has a particular focus on extending the CPM's network.

### Composition

The External Advisory Board members have a wide range of expertise, including industry and academic journal editorship as well as experience reflecting the CPM's main audiences of researchers, clinicians, academics, policy makers and the public.

**CPM core team, November 2023** (L-R): Dr Susie Weller, Dr Padraig Dixon, Dr Ali Kay, Catherine Lidbetter, Professor Anneke Lucassen, Thea Perry, Sally Sansom, Dr Emilie Wigdor, Dr Sarah Briggs. Not pictured: Dr Rachel Horton





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