



ONCOLOGY RESEARCH FOR OPTIMAL PATIENT VALUE

- A SYSTEMS APPROACH

INTRODUCTION

Cancer not only impacts a growing number of patients and families, but also challenges our whole society and healthcare system. Belgium is one of the world's leading cancer research countries and despite the high resources invested, this does not always benefit patients as much as it could.

The King Baudouin Foundation (KBF) is building a coalition of cancer research stakeholders who share a vision of how to make cancer research work better for patients.

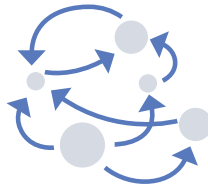
In 2020, we organized a future-oriented, strategic reflection* on the Belgian oncology research system with a broad group of stakeholders. The group represented actors in the Belgian oncology research landscape, complemented by several international experts to ensure our connection with oncology research in Europe. The guiding question put forward as starting point for the strategic reflection was as follows:

How can we ensure that cancer patients have rapid and affordable access to the results of evidence-based, publicly and philanthropically funded studies, to improve their life expectancy and quality of life?

This process gave detailed insight into the dynamics which can cause the current system to underperform, creating less patient value than it should. The stakeholders were able to agree on a shared vision of how oncology research could ameliorate such dynamics and optimize for patient value.

An initial set of recommendations was made, embodying the perspectives and aspirations of the stakeholders. A very important result of the process has been the creation of a coalition of stakeholders. We hope that they are willing to help bring the recommendations to life.

We have taken the first steps towards a future in which patients, stakeholders and our whole society will benefit more from the enormous resources that are mobilized to combat cancer. The key to building momentum, and expanding the scope and ambition of these efforts, will be securing buy-in from a broader coalition of stakeholders in Belgium and beyond. At KBF, we have the intention to continue to take on the role of trusted convenor and agent of change in this process.



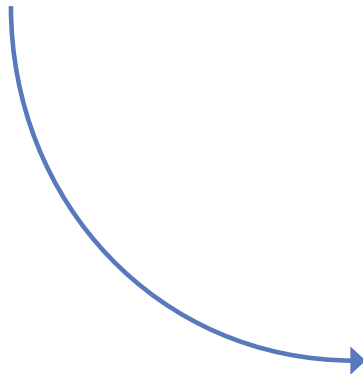
The Belgian oncology research system is currently not generating as much patient value as it could.

That is the main conclusion from our in-depth analysis. The multitude of perspectives provided by a broad group of stakeholders allowed us to compose a big picture of the Belgian oncology research system. The complementary insights generously provided by everyone around the table helped us to unravel the many interacting drivers that lead to the perceived lack of patient value. The drivers range from the operational to the strategic level and span the whole ecosystem of actors. These actors include the private sector, shareholders, academia, patients, patient organizations, funding agencies, regulators, payers and others.

Crucial factors that undermine the potential of the system to bring valuable innovations to cancer patients include institutional fragmentation, the pervasiveness of profit maximization in the pharma business model combined with their institutional monopoly, dynamics within and between treatment centers, challenges related to clinical trials and a lack of patient involvement in key decisions. The growing complexity and sophistication of cancer research, as reflected in increasing personalization of treatments, and chronification of the disease has made it more urgent than ever to address the challenge of bringing valuable innovations in a timely and more equitable way to those who need them.

The diagnostic systems map also reveals that it is conceptually impossible to separate the oncology research system funded by public and philanthropic resources, from the industry-funded research system. They interact with each other in a myriad of ways.

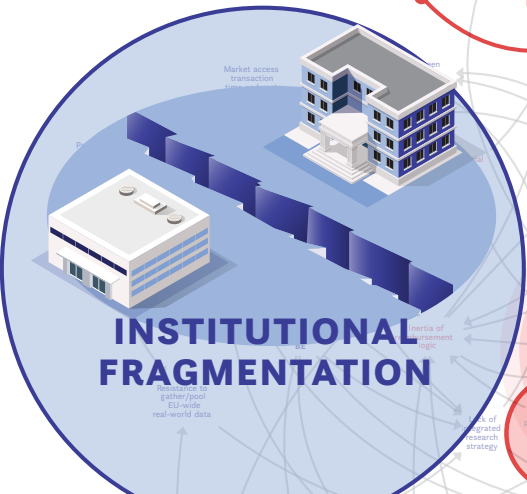
The diagnostic systems map
is comprised of more than 90
identified drivers
which interact with each other,
leading to suboptimal patient value.
Enclosed clusters of drivers reflect
domains where the system does not
contribute to patient value as much
as it ideally should.**



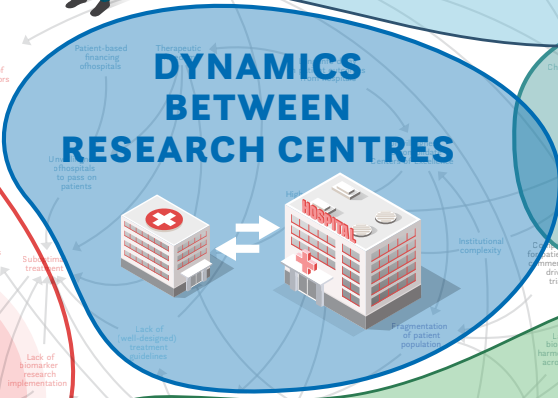
COMMUNICATION WITH PATIENTS



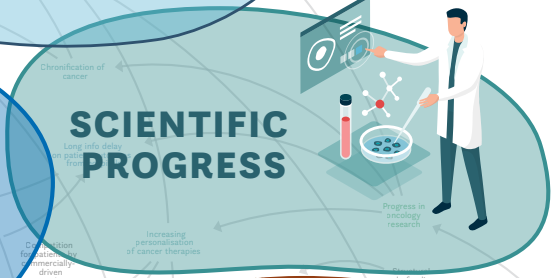
PATIENT INVOLVEMENT



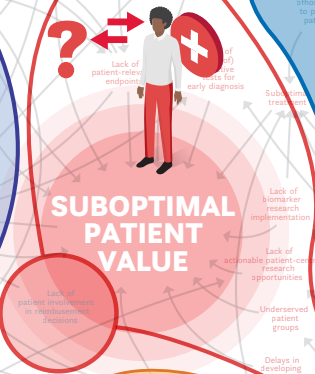
DYNAMICS BETWEEN RESEARCH CENTRES



SCIENTIFIC PROGRESS



SUBOPTIMAL PATIENT VALUE



CHALLENGES IN CLINICAL TRIALS



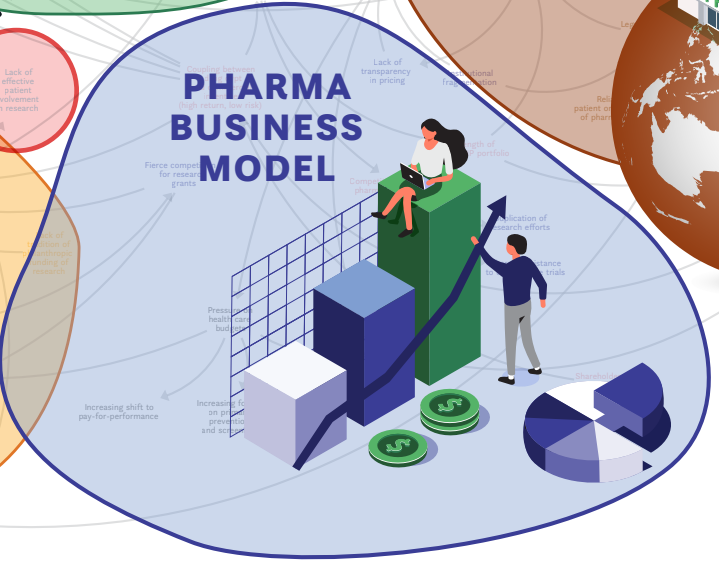
PHARMA INSTITUTIONAL MONOPOLY



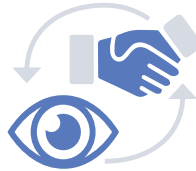
CHALLENGES IN NON-COMMERCIAL RESEARCH



PHARMA BUSINESS MODEL



SHARED VISION



Moving towards a Belgian oncology research system that optimizes for patient value requires a positive outlook.

This is an aspiration that is supported by a broad range of stakeholders. Our future-oriented strategic reflection allowed stakeholders to co-create a shared vision of Belgian oncology research that deliberately counters the weaknesses of the current oncology research system. And it reveals the essential functions or activities that need to be present in a system of oncology research that is rigorously oriented towards generating patient value.

The shared vision offers an aspirational, purposeful outlook and helps build awareness of the whole system. The core module '**defining and assessing patient value**' orients the research towards generating patient value and orchestrates all aspects related to research, including '**agenda setting and funding**' and '**incentivizing innovation**'.

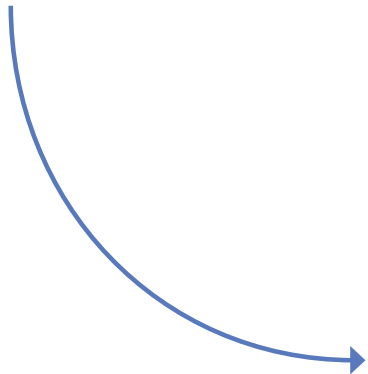
The connection between '**conducting research**' and '**learning by doing**' in the model provides a foundation for dialogue and action. This is particularly important in light of the growing complexity and sophistication of cancer research, as reflected in the increasing personalization of treatments. The shared vision also welcomes contributions of both commercial and non-commercial actors as well as hybrid partnerships. Overall, it aims to catalyze a better coordination of key actors in Belgian oncology research, helping them align their various trajectories synergistically, using the shared ambition of creating more patient value.

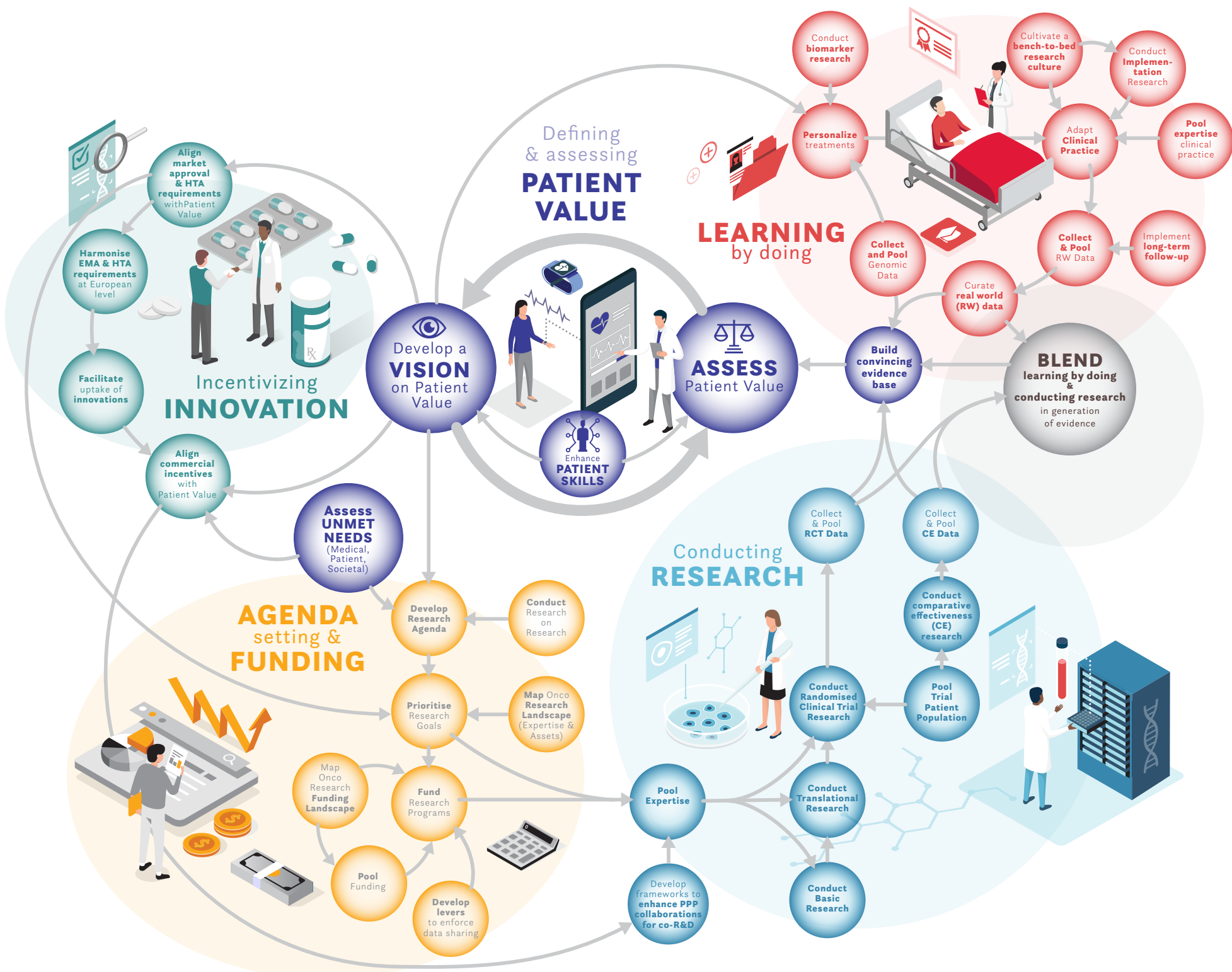
**An outlook for a
Belgian oncology research system
optimizing for patient value.**

The vision is comprised of

5

modules.





Defining & assessing PATIENT VALUE

Develop a
VISION
on Patient Value

ASSESS
Patient Value

Enhance
PATIENT SKILLS

INNOVATION

AGENDA setting & FUNDING

LEARNING by doing

CONDUCTING RESEARCH

BLEND
learning by doing &
conducting research
in generation of evidence

Assess UNMET NEEDS
(Medical, Patient, Societal)

Develop Research Agenda

Prioritise Research Goals

Fund Research Programs

Map Onco Research Funding Landscape

Pool Funding

Develop levers to enforce data sharing

Conduct Research on Research

Map Onco Research Landscape (Expertise & Assets)

Pool Expertise

Develop frameworks to enhance PPP collaborations for co-R&D

Collect & Pool RCT Data

Conduct Randomised Clinical Trial Research

Conduct Translational Research

Conduct Basic Research

Collect & Pool CE Data

Conduct comparative effectiveness (CE) research

Pool Trial Patient Population

Personalize treatments

Collect and Pool Genomic Data

Build convincing evidence base

Conduct biomarker research

Curate real world (RW) data

Collect & Pool RW Data

Implement long-term follow-up

Cultivate a bench-to-bed research culture

Adapt Clinical Practice

Conduct Implementation Research

Pool expertise clinical practice

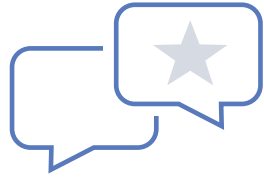
Align market approval & HTA requirements with Patient Value

Harmonise EMA & HTA requirements at European level

Facilitate uptake of innovations

Align commercial incentives with Patient Value

RECOMMENDATIONS

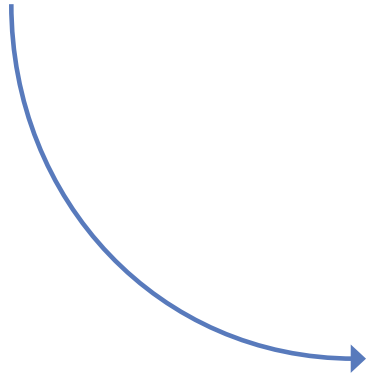


The development of a shared vision allows the formulation of a set of recommendations that encompass perspectives and aspirations from different stakeholders. The recommendations aim to improve the current oncology research system. They provide an actionable bridge between the weaknesses of the current Belgian oncology research system and the shared vision of better patient value creation. At this point, we have collected twelve recommendations that connect at different points to the shared vision. Five out of twelve recommendations are associated with the module 'defining and assessing patient value'. This confirms the importance of developing a defensible and patient-informed approach to the challenge of how we define, measure and target patient value.

These recommendations are particularly valuable for two reasons. First, they represent a clear mandate, because of the consensus and dialogue from which they emerged. Second, because this dialogue has involved a wide range of stakeholders, the recommendations can provide a practical basis for aligning the complex perspectives and aims of the many different types of actors working in Belgian oncology research.

While it is important to note that the current set of recommendations is neither comprehensive nor final, our aim is to use these recommendations as a starting point and move towards concrete actions together with actors in Belgian oncology research whilst considering and aligning with existing initiatives.

The current set of
12
recommendations.



OPERATIONAL

Facilitate access to innovative therapies in clinical studies for rare gene abnormalities/ rare tumors independent of location of center and patient

Differentiate survivorship research by age cohort

Leverage data sharing

Create a platform for integration of different data streams

STRUCTURAL

Develop trial programs that assess added patient benefit with speed and flexibility

Operationalize the assessment of unmet needs

Mobilize/recognize/support GPs as key partners in prevention, early diagnosis, research and survivorship

Enhance collaboration of/with HTA/ regulatory bodies

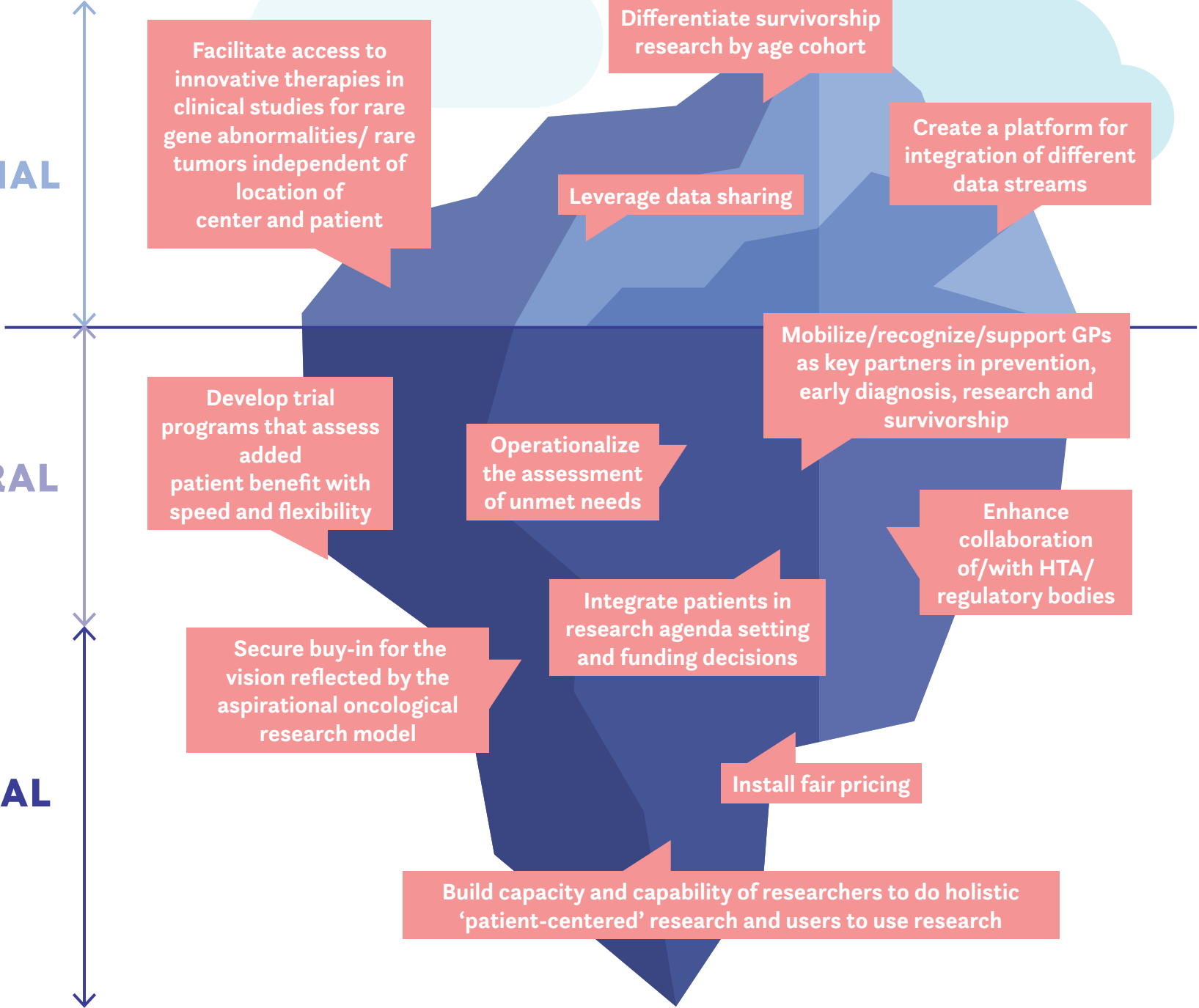
CULTURAL

Secure buy-in for the vision reflected by the aspirational oncological research model

Integrate patients in research agenda setting and funding decisions

Install fair pricing

Build capacity and capability of researchers to do holistic 'patient-centered' research and users to use research



OUR QUESTIONS

1

What do you consider as the most valuable of the strategic reflection?

2

What part/outcome of the strategic reflection is the most important for you?

3

Do you have further recommendations? If possible, please explain and explain how they connect with our vision presented?

4

Do you have suggestions for actors and/or stakeholders and/or ambassadors to inform/consult/involve when moving forward? Please elaborate on the why of your suggestion. Please also provide details about organization, names, roles, etc.

5

Do you know initiatives that align with the current set of recommendations?

7

Do you want to be involved in the future? Yes/No - Why? How?

6

Do you have suggestions for events or conferences (Belgium & Europe/International) that would be interesting for the KBF team to attend? Please provide details on the suggestions, including which meeting, conference, timing, etc.

8

Does your organization want to be involved in the future? Yes/No - Why? How?

FOR DETAILS ON
METHODOLOGY AND RESULTS,
PLEASE CHECK THE FULL
REPORT:



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Title

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Footnotes

- * ShiftN set up a disciplined process of exploration (of contextual factors that orient the ecosystem) and design (of a high-performance oncology research model). The shiftN team was supported by a Guidance Committee composed by KBF: Lydie Meheus (Anticancer Fund), Frank Hulstaert (Belgian Health Care Knowledge Centre), Yannis Natsis (European Public Health Alliance), Jean-Benoît Burrion (Jules Bordet Institute).
- ** The diagnostic systems map is not the one and only perspective possible, but it provided a good foundation to co-create a shared vision for a high-performance oncology research model.



King Baudouin
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Working together for a better society