D1.6 Workshop on First version of SRIA

Karolinska Institutet

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Deliverable Abstract
This Deliverable aims to summarize all activities and collected input presented during the **"Workshop on First version of SRIA"** that took place at Karolinska Institutet, Stockholm, Sweden on October 1st, 2024. The Workshop was attended by all PROPHET Project Partners, Advisory Board members and several external Stakeholders. To structure the workshop with stakeholders we went back to the original call text, as well as experiences from PROPHETs work to date to identify five discussion topics to reflect the nine challenges listed in the draft SRIA, namely: Scope of SRIA; Health Systems integration; Changing Behaviours; Governing Personalized Prevention; and Data Integration across Sectors. The workshop was arranged in the mode of a world café, where the stakeholder groups circulated at five stations to discuss the different topics concerning the SRIA. Each discussion group was led by a moderator with expert competence in the field, and a dedicated notetaker to ensure the documentation of the discussions. Stakeholders gave valuable feedback and comments on the first draft SRIA, focusing both on the challenges already written up in the SRIA, but also prompted us to add two more challenges – a "framing" one, and one on behavioural science – in subsequent revisions of the SRIA. The stakeholders will be engaged to give feedback on new versions of the SRIA.

Keywords
Workshop, public health, behaviour.

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Executive summary

This deliverable aims to summarize all group discussions and activities presented during the "Workshop on first version of SRIA" held with stakeholders on October 1st, 2024 in dual-mode, on-site in Stockholm, Sweden, and online via the Teams platform. The workshop was attended by all PROPHET Project partners, Advisory Board members, and several external stakeholders.

Stakeholders gave valuable feedback and comments on the first draft SRIA, focusing both on the challenges already written up in the SRIA, but also prompted us to add two more challenges – a “framing” one, and one on behavioural science – in subsequent revisions of the SRIA.

In this Deliverable, readers can consult the highlights and conclusions of the discussions in the Workshop, challenges identified and the consortiums’ forward plans on developing the SRIA further. Additionally, the complete list of meeting participants, including the names and

affiliations of stakeholders, is provided, as well as the workshop AGENDA. Finally, original notes from the working groups are attached to this document.

List of participants

Name	Affiliation	partner/ stakeholder
Alessandra Maio	Università Cattolica del Sacro Cuore, Rome	consortium
Alexandra Costa	INSA	consortium
Alexandra Gyllenberg	Karolinska Insitutet, Sweden	consortium
Anant Jani	advisory board, Cambridge	consortium
Angelica Valz Gris	Università Cattolica del Sacro Cuore, Rome	consortium
Angelo Maria Pezzullo	Università Cattolica del Sacro Cuore, Rome	consortium
Anu Reigo	University of Tartu, Estonia	consortium
Arshiya Merchant	ELIXIR	consortium
Astrid Vicente	Instituto Nacional de Saúde Doutor ricardo Jorge	consortium
Beatriz Perez Gomez	CIBER/ISCIII, Portugal	consortium
Bianca Ferraiolo	Cittadinanzattiva - Active Citizenship Network	consortium
Carla van El	AmsterdamUMC	consortium
CarlJohan Sundberg	Karolinska Insitutet, Sweden	consortium
Charlotte Alcouffe	G.A.C. Group	consortium
Cristina Barahona López	Instituto de Salud Carlos III	consortium
Cristina Costa	Instituto Nacional de Saude Doutor Ricardo Jorge (INSA), Portugal	consortium
Elena Plans Beriso	CIBER/ISCIII	consortium
Estefania Callejas De Luca	European Patients Forum	consortium
Eugenio Di Brino	ALTEMS, Catholic University of Sacred Heart (UCSC)	consortium
Eva Fadil	G.A.C. Group	consortium
Eva Van Steijvoort	KU Leuven	consortium
Evelina Flodquist	Karolinska Insitutet, Sweden	consortium
Filippo Rumi	ALTEMS Advisory	consortium
Ingrid Kockum	Karolinska Insitutet, Sweden	consortium
Jhon Alvarez Ahlgren	Karolinska Insitutet, Sweden	consortium
Laura Blackburn	PHG Foundation	consortium
Loes Lindiwe Kreeftenberg	AmsterdamUMC	consortium
Louiza Kalokairinou	ELIXIR Hub	consortium
Luigi Russo	Università Cattolica del Sacro Cuore, Rome	consortium

Magda Chegkazi	ELIXIR Hub	consortium
Mahsa Shabani	Ghent University	consortium
Manuela Pausan	BBMRI-ERIC	consortium
Maria Luis Cardoso	Instituto Nacional de Saúde Doutor Ricardo Jorge (INSA)	consortium
Mario Masiello	Università Cattolica del Sacro Cuore, Rome	consortium
Markus Perola	Finnish Institute for Health and Welfare	consortium
Michele Basile	ALTEMS, Catholic University of Sacred Heart (UCSC)	consortium
Pascal Borry	KU Leuven	consortium
Patricia Cervera de la Cruz	Ghent University	consortium
Pragathy Kannan	The Finnish institute for health and welfare (THL)	consortium
Roberta Pastorino	Università Cattolica del Sacro Cuore, Rome	consortium
Roza Adany	Department of Public Health and Epidemiology, Faculty of Medicine, University of Debrecen, Debrecen, Hungary	consortium
Sara Farina	Università Cattolica del Sacro Cuore, Rome	consortium
Serena Scollen	ELIXIR	consortium
Stefan Swartling Petersen	Karolinska Insitutet, Sweden	consortium
Stefania Boccia	Università Cattolica del Sacro Cuore, Rome	consortium
Tommaso Osti	Università Cattolica del Sacro Cuore, Rome	consortium
Yasemin Zeisl	European Patients' Forum (EPF)	consortium
Alessandra Veronese	AISED	stakeholder-Online
Alexandru Costescu	European Commission	stakeholder-Online
Alexios-Fotios Mentis	BGI Genomics	stakeholder-Online
Baiba Ziemele	Latvian Network of Patient Organizations (LPOT)	stakeholder-Online
Delphine Ferrier	Fondation ARC	stakeholder-Online
Francesco Florindi	Thermo Fisher Scientific	stakeholder-Online
Giulia Maria Rossignolo	Fondazione Regionale per la Ricerca Biomedica (Regione Lombardia, ITALY)	stakeholder-Online
Indridi Benediktsson	European Commission	stakeholder-Online
Konstantinos Makris	Cyprus University of Technoogy	stakeholder-Online
Lina Pérez-Breva	Vaccine Research-FISABIO Public Health	stakeholder-Online
María Brion	Instituto de Investigación Sanitaria de Santiago	stakeholder-Online
Maria Teresa Silveira Dias Flor-de-Lima	Sociedade Portuguesa de Literacia em Saúde, SPLS	stakeholder-Online
Marius Geanta	Centre for Innovation in Medicine	stakeholder-Online

Martin URIARTE ASTEINZA	European Commission - DG RTD	stakeholder-Online
Mary Lynne Van Poelgeest	World Federation of Incontinence and Pelvic Problems - WFIPP	stakeholder-Online
Mercy Wanjala	AfroPHC	stakeholder-Online
Monika Frenzel	The French National Research Agency	stakeholder-Online
Nancy ABOU-ZEID	Fondation ARC pour la recherche sur le cancer (France)	stakeholder-Online
Patricia García Sanz	AETSA-FPS	stakeholder-Online
Rosa Almeida	Intras Foundation	stakeholder-Online
Rui Amaral Mendes	Faculty of Medicine of the University of Porto	stakeholder-Online
Tessel Rigter	AmsterdamUMC	stakeholder-Online
Wenya Wang	Beijing Tsinghua Changgung Hospital	stakeholder-Online
Anders Ahlsson	Region Stockholm Health and Medical Care Administration, Sweden	stakeholder - onsite
Angelika Rzepka	AIT Austrian Institute of Technology GmbH	stakeholder - onsite
Anton Holmgren	Region Halland (Göteborgs Universitet) Sweden	stakeholder - onsite
Avesta Starkholm	Medtech4Health	stakeholder - onsite
Borut Peterlin	Clinical Institute of Genomic Medicine, University Medical Ceneter Ljubljana	stakeholder - onsite
Helena Linge	Region Halland, Sweden	stakeholder - onsite
Helle Mölsted Alvesson	Karolinska Institutet, Sweden	stakeholder - onsite
Henk Jan Guchelaar	Leiden University Medical Center (LUMC)	stakeholder - onsite
Ivana Cattaneo	Novartis	stakeholder - onsite
Kristina Ström-Olsson	Head of Personal Insurance Commercial Sweden, Nordic Health Strategist	stakeholder - onsite
Magnus Thyberg	Region Stockholm Health and Medical Care Administration, Sweden	stakeholder - onsite
Malin Eklund	Vinnova, Swedish Innovation Agency	stakeholder - onsite
Saba Hussein Gore	British Embassy, Sweden	stakeholder - onsite
Ylva Trolle Lagerros	prof. cardiovascular prevention, Karolinska Institutet, Sweden	stakeholder - onsite

Agenda

Day 2: Tuesday 1 of October		
13.30	Introduction: Presentation of PROPHET and the objectives of the Stakeholder session	S. Boccia (UCSC)
13.45	Stakeholder session: introduction to workshop and expected outcomes	S. Swartling Peterson (KI)
14.00	Stakeholder session: discussions in smaller groups	
15.00	*Coffee break*	
15.30	Stakeholder session continued: discussions in smaller group	
16.30	Reporting from the groups, concluding remarks	
17.30	*Adjourn*	
18.00	*Dinner with Stakeholders* (Haga Bottega Restaurant situated in Elite Hotel Carolina Tower, Eugeniavägen 6, Stockholm)	

Link for online participation: https://teams.microsoft.com/l/meetup-join/19%3ameeting_OThjMWE4YTQtMjg4ZS00NGNmLTgyODItNzIxOTNkODA5MTE2%40thread.v2/0?context=%7b%22Tid%22%3a%22bff7eef1-cf4b-4f32-be3d-a1dda043c05d%22%2c%22Oid%22%3a%2222f35f78-77b8-4155-9302-2f5606273773%22%7d

Workshop summary

To structure the workshop with stakeholders we went back to the original call text, as well as experiences from PROPHETs work to date to identify five discussion topics listed below to reflect the nine challenges listed in the draft SRIA.

The workshop was arranged in the mode of a world café, where the stakeholder groups circulated at five stations to discuss different topics concerning the SRIA. Each discussion group was led by a moderator with expert competence in the field, and a dedicated notetaker to ensure the documentation of the discussions. The discussion topics are covering the nine challenges in the SRIA as described below. The stakeholders were divided in five groups onsite and one online, based on their affiliation and background, to ensure a diversity of people in each group.

Topic A. SCOPE AND COVERAGE, *moderator Carl Johan Sundberg, MD and Professor at the Department of Physiology and Pharmacology, Karolinska Institutet. Dean for Karolinska Institutet North.*

This topic covers SRIA Challenge 1: Continuous evidence synthesis system supporting personalised prevention, and Challenge 3: Data collection and integration, and Data Infrastructure

Topic B HEALTH SYSTEMS INTEGRATION, *Moderator Jhon Alvarez Ahlgren, Ph.D Community nutrition and physical activity, Global Public Health department, Karolinska Institutet.*

This topic covers SRIA Challenge 2: The PROPHET Framework implementation, Challenge 3: Data collection and integration, and Data Infrastructure, and Challenge 9: Ethical, Legal, Social Issues (ELSI)

Topic C CHANGING BEHAVIOURS. *Moderator Helle Mölsted Alvesson, medical anthropologist, Ph.D in Public Health, Karolinska Institutet.*

This topic covers Challenge 4: Responsible Research and Innovation (ERIC) and Challenge 5: Community Engagement and trust

Topic D GOVERNING PERSONALIZED PREVENTION for all. *Moderator Stefan Swartling Peterson, MD and Professor of Global Transformation for Health, Karolinska Institutet.*

This topic covers Challenge 5: Community Engagement and trust, Challenge 6: Health Professionals and Policy Makers involvement, Challenge 7: Regulatory aspects and synergy with private sector and Challenge 8: Access, Equity and Coverage

Topic E. DATA INTEGRATION ACROSS SECTORS. *Moderator Malin Eklund VINNOVA, the Swedish Innovation Agency and Arshiya Merchant, ELIXIR*

This topic covers Challenge 3: Data collection and integration, and Data Infrastructure

ONLINE group: discussed all the five topics, *moderator Ingrid Kockum, Professor of Genetic Epidemiology, Karolinska Institutet. Vice-chair Nordic society for human genetics and precision medicine*

After the group discussions, we held a joint session with a panel discussion with representatives from all groups, where important aspects from the different topics were highlighted.

Below is the detailed description of the five topics and the framing of the questions, followed by a summary of the discussions and conclusions /take-home message from each topic. The full-length notes from each group are also attachment to this report.

SCOPE AND COVERAGE: *The call text states: more could be achieved if we could identify early on individuals at higher risk of developing a particular condition, before symptoms occur. As an indicator, two thirds of chronic diseases are thought to be preventable*

Considering the definition and Conceptual model – Does the SRIA adequately address different types of data, and primary/secondary prevention, towards preventing 2/3s of chronic disease?

The discussion focused on gathering diverse types of health-related data to enhance personalized prevention strategies. The key types of data include:

Personal device data: Information from wearables like fitness trackers, providing insights into activity levels, heart rate, and sleep patterns.

Environmental data: Factors like air quality, noise, and green spaces that affect health outcomes.

School data: Surveys and information on students' nutrition, physical activity, and mental well-being, alongside working environments in schools.

Technical data: Diagnostic measures (e.g., breast density) complementing genomic data to assess health risks.

Microbiome data: Collection challenges related to gut microbiota research due to cost and complexity.

Lifestyle data: Including consumption habits, screen time, and school lunch details to gauge overall health behaviors.

Continuous data integration: Establishing frameworks for ongoing health data collection and integration.

Exposure metrics: Assessing screen and device exposure impacts on physical and mental health.

Social interaction metrics: Evaluating the quality of social interactions for promoting healthier work environments.

Work environment data: Examining occupational factors like sedentary behavior that impact health.

Conclusions from discussion:

- The SRIA needs to demonstrate how personalized prevention differs from public health approaches.
- Highlighting success stories and aligning with European initiatives like the European Health Data Space would add value.
- The document should stress the importance of personalized prevention to ease the healthcare system's burden and ensure societal sustainability.
- The document is too long and needs to be shortened to have higher impact and readability.

HEALTH SYSTEMS INTEGRATION. *The call text further says: Personalised prevention therefore holds many promises and would allow for a paradigm shift in the provision and management of healthcare if efforts are coordinated and concentrated at the European and global levels. We are asked to enable: • Evidence based policy decisions for insurers and authorities implementing personalised prevention strategies for all.*

Does the SRIA provide enough insight to advance this paradigm shift for health systems? Consider all health systems building blocks. What could be the role of e.g ***systems innovation and implementation research*** *to advance the health systems paradigm shift?*

Fig.1 Health systems building blocks

Stakeholders explored key elements for implementing innovation in medicine, guided by the World Health Organization's six foundational pillars: Governance, Information, Financing, Service Delivery, Human Resources, and Medicines and Technologies. The aim is to promote population well-being by addressing innovation from multiple perspectives, centred on people.

Key Discussion Points:

Sustainability of innovation: Concerns were raised about the financial burden of adopting new technologies. Clear funding structures are necessary to ensure innovations are sustainable in the long term.

Defining measurable outcomes: Setting clear, measurable outcomes (hard implementational outcomes) are essential for evaluating the success of innovations in improving patient care and system efficiency.

Key drivers of change: Identifying key stakeholders who drive innovation is vital, as they play strategic roles in the implementation process. Involvement from diverse actors—healthcare professionals to policymakers—is crucial.

Multi-level implementation: Implementation occurs at multiple levels (national, local), and actors like employers play a critical role, particularly in workplace prevention strategies.

Role of insurers in prevention: Insurers can facilitate personalized prevention in workplaces by providing tools and resources, integrating preventive measures into insurance policies.

Leveraging existing resources: Building on existing resources, such as patient summaries, can streamline data sharing and improve care continuity.

Multidimensional approach to prevention: A comprehensive strategy should integrate all elements of the WHO model—governance, information, human resources, and technology.

Support networks for prevention: Healthy populations, often targets for prevention, lack support networks. Creating such entities can improve engagement and communication for preventive interventions.

Prevention as health system sustainability: For health systems to remain sustainable, prevention must be integrated. Currently, many systems focus only on therapeutic measures, leaving prevention to external entities.

Social dynamics in prevention: Social dynamics, including peer influence, are critical to the success of preventive programs.

Localized prevention: Strengthening local touchpoints outside hospitals is key for accessible prevention. Governance should focus on both regulation and building public trust to ensure successful implementation.

Political and insurance education: Politicians and insurers need to be educated about precision prevention. Aligning short-term political goals with long-term health outcomes is essential, and insurers must better understand the potential of personalized prevention.

Trust in data handling: Concerns about how insurers handle personal and genetic data, though more prevalent in private healthcare markets like the U.S., remain smaller in Europe due to predominantly national health insurers.

Conclusions from discussion:

- Sustainability requires clear funding and support: For innovations in healthcare to be sustainable, there must be clear financial structures that define who will bear the costs—whether governments, insurers, or healthcare providers.
- Prevention is key to health system sustainability: Integrating preventive measures into healthcare systems is essential for long-term sustainability. Focusing solely on therapeutic interventions limits the ability to reduce the future disease burden.
- Stakeholder engagement is crucial for innovation: Successful implementation of health innovations relies on involving a diverse range of stakeholders, including healthcare professionals, employers, insurers, and policymakers, to drive change.
- Public trust and education are essential: Building trust in how personal and genetic data is handled is important. Additionally, educating both politicians and insurers about the benefits of personalized prevention is necessary to ensure its widespread adoption.

CHANGING BEHAVIOURS.

From the call text: successful strategies will require holistic approaches, taking into account behavioural and lifestyle factors.

We advance in predicting risk – but how do we predict adherence to interventions – can also the interventions for behaviour change be personalized? (Data Science) Where does behavioural research come in as a research need and with which agenda? – For Individual behavior change. And for Societal?

Personalized prevention involves implementing health interventions at three interconnected levels: societal, community, and individual. The biological and genetic basis for behaviors, such as addiction, offers opportunities to tailor interventions. The private sector plays a crucial role in shaping behaviors, especially through data collected from social media and advertising,

which can be useful for healthcare systems to personalize prevention strategies. However, a major challenge is the lack of knowledge and education on behavioral change, for example in clinical settings. It's essential to consider geographical, cultural, and socio-economic factors when structuring interventions, and recognize that individuals must take responsibility for their health, though they can't be forced to change. Positive, personalized messages, not fear-based tactics, should guide behavior change efforts. The complexity of implementing personalized prevention involves the importance of both genetic and behavioral factors, and the need for collaboration between public health systems and the private sector.

Conclusions from discussion:

- Interconnected levels for personalised prevention: Personalized prevention should operate across societal, community, and individual levels, ensuring consistency and harmonization between these approaches to effectively address health behaviors.
- Genetic and behavioral basis of health: Understanding the genetic basis of certain behaviors (e.g., addiction) allows for more tailored and effective health interventions, emphasizing the role of biology in shaping behaviors.
- Need for better behavioral change research and education: Despite available data, there is a significant gap in research on how to effectively change behaviors and educate healthcare professionals to support this, especially in clinical practice.
- Role of private sector and data utilization: The private sector's influence on behavior through advertising and social media, along with its data collection, offers healthcare systems valuable insights for personalizing prevention strategies.
- Behavioral science is a challenge that needs to be addressed in the SRIA.

GOVERNING PERSONALIZED PREVENTION for all.

From the call text we have the expected outcome: Policy makers, public health services, industrial stakeholders and citizen associations will be empowered to act by a coordinated, harmonised and comprehensive approach to personalised prevention research for all, across Europe. The SRIA considers ethics and equity- sufficiently? Effective prevention requires multisectoral collaboration (health, education, social services, food, city planning, environmental etc.). What is the research and innovation agenda for multisectoral governance for health? And for citizen involvement?

Stakeholders discussed the significant barriers to effective preventive health efforts, particularly in relation to health literacy, access to care, socioeconomic determinants of health, health policy, community involvement, and the role of digital health technologies.

Health literacy and education: There is a widespread lack of health literacy, especially among lower-educated populations, which hampers personalized medicine and preventive health initiatives. Many communities struggle to understand health issues, particularly in the realms of genetics and genomics. Effective communication and education strategies are essential, especially for marginalized communities and ethnic groups with lower participation in genomic testing.

Barriers to access to care: Access to preventive health care is inequitable, with socio-economic challenges and a divide between urban and rural areas exacerbating the issue. Those with lower education levels often lack knowledge about health and are less likely to engage in preventive care. Addressing these inequities requires the use of role models and community ambassadors to engage underserved populations.

Socioeconomic determinants of health and nutrition: Socioeconomic factors greatly influence health outcomes, with disadvantaged backgrounds limiting access to preventive health information and services. Poor nutrition and unhealthy eating habits are prevalent in low-income communities, necessitating a broader approach that includes creating supportive environments and addressing food production regulations.

Health policy, regulation, and the role of governments: Effective health interventions require political support and regulation, such as taxing unhealthy foods and promoting healthier alternatives. Current preventive health funding is insufficient, and policies need to prioritize preventive care and address the underlying social determinants of health. Governments must also collaborate with health insurance providers to incentivize healthy behaviors and ensure equitable access to personalized health solutions.

Community involvement and cultural sensitivity: Engaging communities through local leaders and tailored health programs is essential for addressing health disparities. Cultural sensitivity is crucial in designing effective health interventions that resonate with diverse populations. Including community input in the development of health programs can enhance their effectiveness.

Digital health, data, and technology solutions: Digital health solutions can facilitate personalized health interventions and promote equity; however, challenges in access and digital literacy remain. Collecting and analysing community-specific health data is necessary to tailor health efforts effectively. Collaborative digital health initiatives can improve connections between patients and healthcare providers, fostering better health behaviors.

<u>Conclusions from discussion:</u>

- Improving health literacy is essential: There is a critical need to enhance health literacy, particularly in marginalized populations, to facilitate understanding and engagement in preventive health measures. Strategies should include education in schools and outreach programs to inform those who may not actively seek health information.
- Addressing socioeconomic barriers is crucial: Socioeconomic determinants significantly impact access to healthcare and preventive services. Efforts must focus on reducing inequities in health access by providing tools and support to disadvantaged communities and leveraging community leaders to promote engagement.
- Policy and regulation must support health promotion: Health policies should be standardized and aligned with political agendas to create environments that promote healthy choices, such as taxing unhealthy foods and incentivizing better nutrition. This requires increased funding for preventive healthcare initiatives, especially for children.
- Community engagement is key to success: Effective health interventions must engage communities through culturally sensitive approaches and inclusive practices. Involving community members in the design and implementation of health programs ensures

that initiatives address the unique needs of diverse populations and facilitate broader health equity.

***DATA INTEGRATION** ACROSS SECTORS*

The SRIA elaborates on the challenge to integrate genomic and health care data, and the need for solutions in that regard. However, to also integrate contextual, socioeconomic and lifestyle data in predicting risk more accurately, and in personalizing interventions for higher adherence even more sectors need to contribute data, with corresponding legal, ethical, technical challenges. ***WHAT could the SRIA say on this****?*

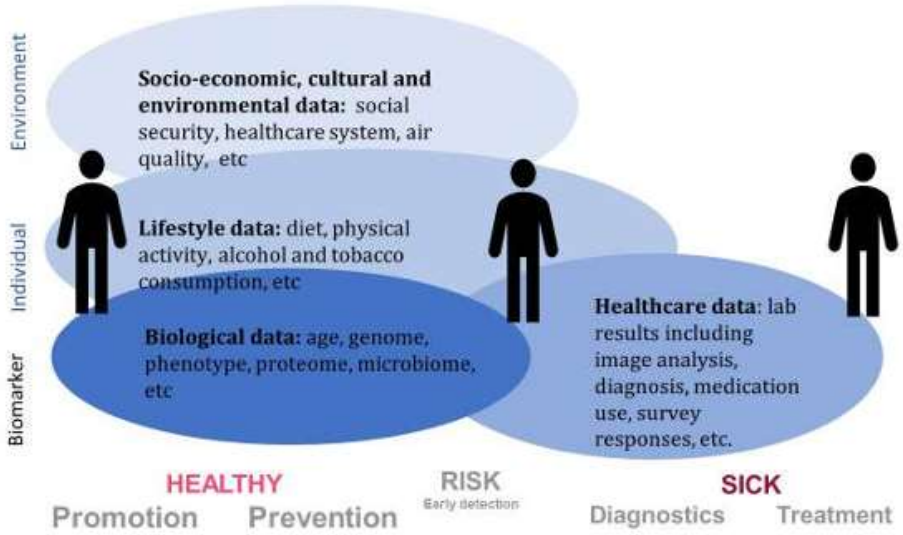

Figure 2. Potential source of information needed to achieve precision and personalization of prevention and treatment across the life course.

The group discussions highlight the importance of motivating individuals to share their data, addressing regulatory concerns, and utilizing existing data for healthcare improvements.

One key point is that the primary obstacle is not only technical integration but also motivating individuals to share their data. There is already a significant amount of health-related data stored on personal mobile devices, but making this data accessible for healthcare purposes requires incentives for individuals to share it. Quality of data should be prioritized over quantity, as excessive data can introduce noise. Longitudinal data is critical for making accurate predictions in healthcare, but integrating research data with health administrative data remains a significant hurdle. EU initiatives are working to address this challenge while ensuring alignment with the European Health Data Space

It was also mentioned that centralized data systems can create bureaucratic hurdles that hinder collaboration. Streamlining consent processes for data sharing could make participation easier for individuals. There is a need for harmonization in electronic health records, as different systems are often used across regions within the same country. Learning from successful data integration practices in other sectors can provide valuable insights for

healthcare. The need for common frameworks and successful case studies to demonstrate the benefits of data integration is emphasized.

Conclusions from discussion:

- Motivating data sharing is crucial: To overcome barriers to data integration, efforts must focus on understanding and enhancing individuals' willingness to share their health data with healthcare systems, addressing privacy concerns, and creating appropriate incentives.
- Regulatory clarity is essential: The perception of strict regulations can inhibit data sharing; hence, establishing clear and supportive regulatory frameworks is necessary to foster confidence among stakeholders involved in data integration initiatives.
- Emphasizing data quality over quantity: Prioritizing high-quality, longitudinal data is vital for effective health predictions and interventions. Leveraging existing data more efficiently can provide valuable insights without the need for new data collection.
- Learning from cross-sector practices: The healthcare sector can benefit from best practices in data integration from other industries, as well as from regional initiatives that demonstrate successful personalized preventive healthcare approaches, facilitating broader implementation across Europe.

Planned action points for the further development of SRIA

The feedback from the stakeholder workshop gave comments on the nine challenges already listed, but also indicated two major topics that needs to be addressed in subsequent versions of SRIA. Therefore, two more challenges will be developed as per below:

"Challenge 0" will be drafted by KI and CIBER.

As illustrated from the discussions the call text, and the PROPHET conceptual model covers the whole range of prevention, if the ambition of preventing up to 2/3s of NCD disease burden is to be realized. While the PROPHET consortium can, and should, point out the multisectoral and multilevel challenges and research and innovation needs to achieve this goal, PROPHET still needs to deliver primarily from its comparative advantage and expertise -that of increasing "precision" in prevention. Furthermore, with a majority of consortium members having expertise in aspects of genomics, this new addition to the SRIA will set out the scope of the SRIA, while calling out the complex systems challenges of actually realizing the "precision prevention dividend" in the context of larger socioeconomic and commercial determinants of health.

"Behavioral challenge" will be drafted by VUMC and THL

Personalised prevention, or precision health, has a large emphasis on determining risk. However, to achieve impact at individual and societal level this is insufficient. Stakeholders,

including individuals, care-givers, and policy-makers, must also act on these improved risk estimates. This introduces a behavioural element, and requires laying out also a behavioural science research and innovation challenge, at individual as well as group/societal level. How can we personalize not just risk estimates, but also interventions for better adherence and impact? A recent review points this out as an area without (published) evidence [1] However, there are e.g. experiences on Socio Behavioural Research from UNICEF and WHO that may stimulate an EU focused research and innovation agenda[2] [3].

This challenge will be added to the ones laid out in the first draft of the SRIA discussed in Stockholm.

Way forward

The existing nine challenges in the SRIA will be updated in light of the Stakeholder discussions, and the stakeholder group consulted in the Stockholm meeting will be approached for commenting on further editions of the SRIA.

Attachments

1. Original notes from workshop

[1] Mauch CE, Edney SM, Viana JNM, Gondalia S, Sellak H, Boud SJ, Nixon DD, Ryan JC. Precision health in behaviour change interventions: A scoping review. Prev Med. 2022 Oct;163:107192. doi: 10.1016/j.ypmed.2022.107192. Epub 2022 Aug 11. PMID: 35963310.

[2] Change Magazine: Why don't you just behave? | UNICEF SBC GUIDANCE

[3] Behavioural insights at WHO - Behavioural Sciences for Better Health