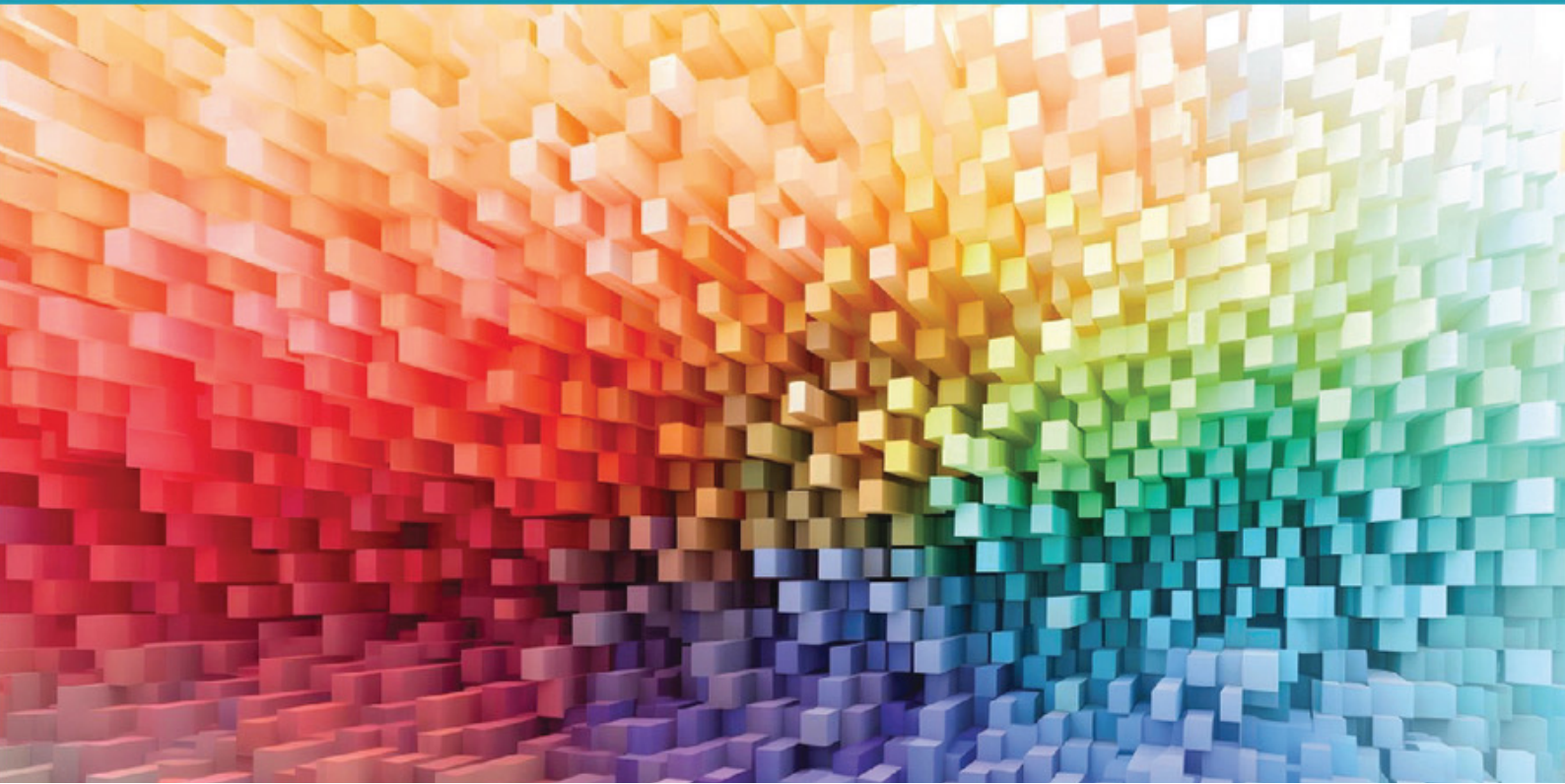


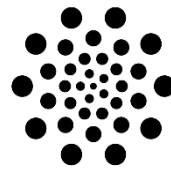
# Amsterdam Cohort Hub

*Connecting data, improving health*

## Roadmap 2024-2025



Steering Committee ACH  
August 2024



## 1. Introduction

Since the launch of the first ACH Roadmap - covering the period November 2023 to July 2024 - we<sup>1</sup> can conclude much has happened around the Amsterdam Cohort Hub (ACH). As the planning period of the first roadmap ended and the ACH-endeavor continues, it is time to develop the second roadmap, covering the period from September 2024 to December 2025. This roadmap builds on the achievements of the first roadmap and incorporates the recommendations from the Roadmap-1 communities and working groups.

This document is a draft prepared by the ACH project management team (PMT) and the Steering Committee. It will be discussed during the Reconnect event of the ACH community on September 3 to advance it to the next phase. Subsequently, the document will undergo further review by the Steering committee on September 10 and the Advisory board on September 17. Given the long-term nature of the roadmap, it has an evolving character, open to adjustments on emerging priorities and experiences. While ownership belongs to the entire ACH community, its maintenance will be managed by the ACH PMT in collaboration with the Steering Committee.

## 2. Flashback

The goal of the first roadmap was to establish a solid foundation for ACH. While we are still exploring the aspirations and boundaries of ACH, we are confident that ACH has developed into an appreciated force within Amsterdam's population-based cohort studies and beyond. This initiative has received great support from cohort staff, who have actively contributed to the working groups and communities and dedicated significant time and effort to strengthening the collaboration between the cohort studies teaming up under the ACH umbrella (figure 1).

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<sup>1</sup> 'We' throughout this roadmap refers to the ACH Steering Committee.

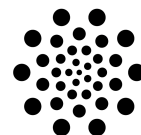


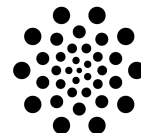
Figure 1: Current ACH-consortium

Noteworthy accomplishments include the many cohort studies that expressed interest in joining the network, the support and collaboration received from other departments, like the Biobank and Research Data Management group, and ACH's participation within Cohorten Hub Nederland, where we are connected with other UMCs.

The more concrete and positive results of our collaboration are:

- The reports our seven working groups, five communities and the Biobank subgroup drafted on a variety of highly relevant cohort-related topics.
- The development of a comprehensive communication plan.
- The formation of an international Advisory Board of distinguished experts in the field of cohort consortia.
- The launch of the ACH-webpage and ACH's LinkedIn page.
- The introduction of the ACH-webinar series.
- The establishment of a joint mission.
- The highly valued and attended first Annual Cohort Conference Amsterdam on July 3, 2024.

Nonetheless, we also experienced some setbacks, and not all goals from the first roadmap were achieved. These latter were carefully documented by the respective groups and accepted early on by the Steering Committee. If still relevant, they will be integrated into this new roadmap. The most important setback we had, was the announcement by the new Dutch government intending to cut the OC&W-sectorgelden facilitating the development of ACH, from 2026 onwards. Fortunately, the Amsterdam UMC Board of Directors, together with the Dutch Federations of UMCs and Universities, immediately announced to fight these cuts, as these funds were guaranteed until at least 2027, and stated that the fixed appointments made on these sectorgelden are secured. Though the political discussion on this topic is still continuing, these responses assures ACH we can continue building a sustainable infrastructure, advancing the impact of our cohort studies.



### 3. Roadmap 2024-2025

Building on past achievements and results, this new roadmap aligns ACH's efforts with its mission. In May 2024, the ACH Steering Committee defined the following mission and vision for ACH (figure 2):

<p><b>Amsterdam Cohort Hub (ACH) - Mission &amp; vision</b>  <b>WHY:</b> To create synergies and foster harmonization among Amsterdam's cohort studies, to help them combine and pool their data, and to improve their visibility, findability and reputation. Thus, we help to advance the reuse and impact of their data and enforce their long-term sustainability.  <b>WHAT:</b> Tapping into deep cohort specific knowledge, we develop a community for collective learning, for sharing knowledge, experience and tools to improve the operations of our cohort studies. Together we build a research data platform with the rich, longitudinal cohort data of our studies for further public health research. In parallel we develop and execute an advocating strategy to strengthen the position of our cohort studies.  <b>HOW:</b> By building a data platform and a network of cohort-staff and -researchers in Amsterdam, stimulating the collaboration and alignment between the involved studies and others, encouraging the re-use and sharing of data, advocating its cohort studies (inter)nationally, and offering infrastructural, data and communication support on cohort level, powered by a spokesperson/director of ACH and support staff.</p>	<p><b>ACH - Unique Value Proposition</b>          Connecting cohort studies from different kinds – population studies, clinical studies – to improve their internal operations, facilitate their collaboration and leverage their external presence, stimulating the reuse of their data and their scientific output, thus amplifying their impact in society and fostering their long-term sustainability.</p> <p><b>Building ACH - Strengthening research from the inside out</b></p> <ol style="list-style-type: none"> <li>1. Identify the opportunities for creating added value by inter-cohort collaboration</li> <li>2. Exchange and develop best practices and standards for improving the operations</li> <li>3. Establish a connected infrastructure to sustain the collaboration and facilitate sharing and enrichment of high-quality data</li> <li>4. Make the story of the ACH-cohort studies heard in national and international institutions</li> </ol>
	<p><b>COHORT HUB LEVEL - RICH DATA RESOURCE</b>          setting up and maintaining a joint cohort infrastructure          FAIR science platform: data sharing, data enrichment through linkage</p> <p><b>COHORT LEVEL - SUPPORT</b>          infrastructural and communication support          stakeholder engagement          team up in research and data organization</p> <p><b>RESEARCH COMMUNITY - SHARE &amp; COLLABORATE</b>          accessible data &amp; data linkage          team up in research &amp; funding on a regional, national and international level</p>

Figure 2: Mission and vision ACH

Unraveling this mission and vision, we identified six key action areas for ACH (figure 3).

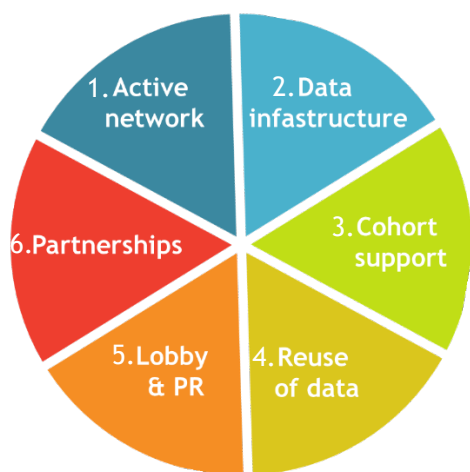
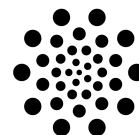


Figure 3: Areas of action ACH

In practical terms, this means:

1. Encouraging systematic and inspiring **knowledge sharing, collective learning, and joint innovation and research** among cohort professionals.



2. Creating a data platform and standardized procedures to **archive FAIR data**, **maintain the quality of the data**, present it in a **data catalog**, and **facilitate data linkage**.
3. **Securing dedicated cohort support** in data services, ethics, legal, ICT, biobanking, and research methods in collaboration with the support units.
4. **Promoting data reuse** by showcase studies, easy and harmonized data access procedures, and a single-entry point to access data for researchers.
5. Executing **lobby and PR activities** to **strengthen the reputation of our studies**, expand their impact, and secure funding.
6. Developing **national and international partnerships** to foster inter-organizational data harmonization and open-source data standards and management.

During the first phase of ACH's existence, the project organization evolved into a more concrete structure, and the roles of the different entities became more clearly defined (Figure 4).

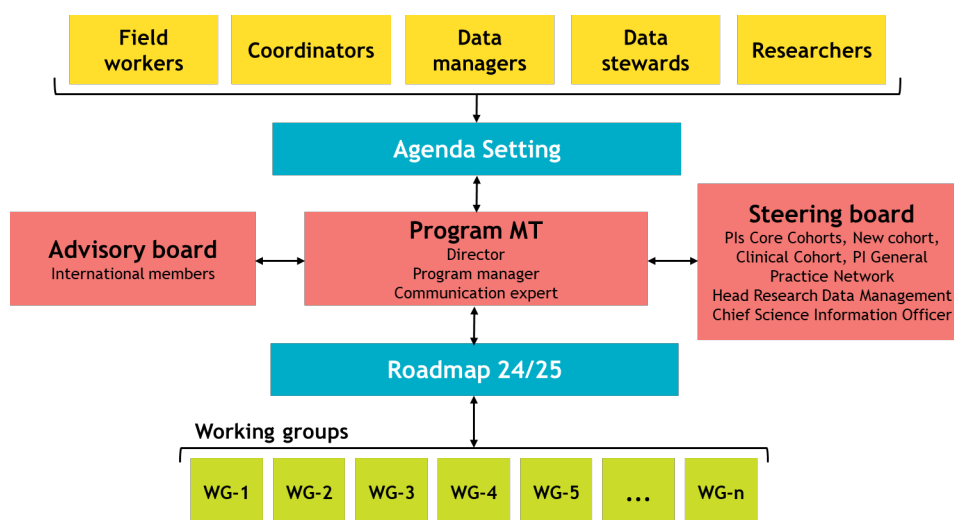


Figure 4: ACH structure phase 2

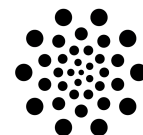
The communities, where likewise professionals from ACH cohort studies meet and discuss relevant cohort issues, are evolving into agenda-setting bodies within ACH. Their input informs the PMT in setting priorities and developing new plans. The Steering Committee serves as the overarching supervisory authority of ACH, with support from the Advisory Board, which provides expert insight into our development and direction. At the operational level, ACH thrives on the efforts of our multidisciplinary, multi-cohort working groups, which focus on specific assignments.

In this roadmap, we begin by outlining the future of our communities, followed by that of our working groups.

## 4. The ACH-communities

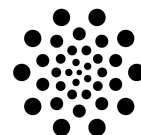
Under the first roadmap, we established five ACH communities, bringing together similar professionals from each participating cohort study. All communities found great value in regularly connecting with peers from other cohort studies and recommended continuing these meetings. In the first phase, the communities were tasked with specific



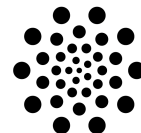


assignments. From now on, the communities are expected to function as largely self-organizing bodies, managing their own agendas and programs. Based on their phase 1 reports, we anticipate the following next steps from each community.

<i>Community</i>		<i>Follow-up phase 2</i>
1.	Fieldworkers' community	<p>Based on the community's recommendations for follow-up actions (as detailed on pages 10 and 11 of their report), the Steering Committee has prioritized the following:</p> <ol style="list-style-type: none"> <li>1. The development of the proposed recruitment handbook including an informed consent template.</li> <li>2. The completion of the overview of material resources currently used for data collection, to be integrated into the ACH-knowledge platform (see 5.4).</li> <li>3. The construction of a field guide with best practices for the training and development of fieldworkers.</li> </ol> <p>We also encourage the community to invite field worker representatives from other cohort studies to join this community. The Steering Committee fully supports the community's plan for further collaboration. Should there be a need to establish specialized working groups to focus on any of the aforementioned priorities, please share this with the ACH PMT.</p>
2.	Data stewards' community	<ul style="list-style-type: none"> <li>- The initial work on clarifying the role and responsibilities of data stewards within the field of cohort studies will be handed over to the ACH PMT (see 5.7), to bring this topic further in collaboration with the Amsterdam UMC HR department, RDM and our ACH-data stewards.</li> <li>- Considering the continuation of the community, it is recommended to first assess its sustainability by seeking new participants from cohort studies that are not yet represented. Secondly, discussions should be held with the data managers' community and the RDM data stewards' network to explore possibilities for collaboration or merging of groups.</li> </ul>
3.	Data managers' community	<ul style="list-style-type: none"> <li>- The intended expansion of the inventory of data management tools currently in use to guide new cohort studies in their choice of tools, is supported. For presenting and communicating the findings, connecting with the ACH-knowledge platform seems apposite (see 5.4).</li> <li>- The community's investigation into the data sharing platforms currently in use by the different cohort studies is greatly appreciated by the Steering Committee, as well as the plan to advance this topic. The community is advised to collaborate on this topic with the Coordinators' community, to work towards harmonizing the data-sharing procedures over the next year. If forming a joint working</li> </ul>



		<p>group is deemed the best approach, we are open for this initiative.</p> <ul style="list-style-type: none"> <li>- In terms of the community's continuation, we support the proposed collaboration with the RDM groups mentioned in their advice and suggest including the Data stewards' community in this effort.</li> </ul>
4.	Coordinators' community	<ul style="list-style-type: none"> <li>- The Steering committee supports the community's priority of harmonizing data-sharing policies in the coming year. We recommend that the community begins drafting a work plan in collaboration with the Data managers' community, evaluating the current data-sharing platforms. If you determine installing a joint working group is the best approach, we are open to facilitate this.</li> <li>- The community's findings related to knowledge transfer will be transferred to the ACH PMT to see how we can leverage our valorization and impact (see 5.6).</li> <li>- For the organization of the 2025 Annual Cohort Conference, a new preparation team will be formed. We assume the community will be available to share insights and evaluations from the 2024 conference (see 5.5).</li> <li>- Regarding the future of the community, we would prefer to see all cohorts represented and actively participating, rather than rotating cohort studies in and out of the community. If the community encounters challenges in this regard, please bring them to the attention of ACH PMT. The Steering Committee supports the community's role in signaling issues and looks forward to your future reports.</li> </ul>
5.	Researchers' community	<ul style="list-style-type: none"> <li>- The Steering committee highly appreciates the community's ambitions and plans for the next phase. However, we recommend setting clear and realistic priorities. We agree that a Researchers' community focused on cohort research complements the APH Methodology program and is crucial. We encourage the community inviting all cohort studies and their researchers to participate.</li> <li>- We suggest discussing with the Advanced Methodology working group whether combining the two groups is feasible and appropriate (see also 5.2).</li> <li>- Developing showcases that combine data from different cohort studies, to the Steering Committee has a high priority. We suggest connecting with Stress in Action and/or NTR research on microbiome and well-being. Both represent examples of cross-cohort collaboration and valuable showcases. If the community considers developing a concrete project plan for this, please use the template of Appendix 1. Thus this effort becomes part of the monitoring system of ACH.</li> </ul>



	<ul style="list-style-type: none"><li>- Regarding the follow-up on the overview of the aims, samples and measures of the ACH-cohort studies, we would recommend completing this in collaboration with the Advanced Methodology group, in such a way that it can become part of the ACH-knowledge platform that is to be developed (see 5.4).</li><li>- For enhancing our funding efforts, we suggest to indeed develop a sample text on ACH for researchers and if appropriate to involve a Grant Support officer to explore joint and new grant proposal opportunities.</li></ul>
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#### 4.1 POSITIONING

Recognizing the communities as valuable contributors to future agenda-setting for ACH (see figure 4), we are introducing a new platform to provide regular input from the communities to the ACH PMT. We invite each community to delegate a member to join the Extended PMT. This team will meet quarterly to discuss the commonalities and progress of the ACH program, with community participation rotating annually. Additionally, this platform will allow communities to align their efforts and share initial results.

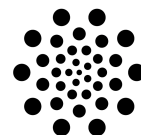
In phase 1, each community was assigned a Steering Committee member as a mentor to provide coaching and support. Unfortunately, this approach didn't work out as expected, primarily due to time constraints on the part of the mentors. However, we still believe in the value of connecting each community with a cohort Principal Investigator (PI). Given Steering Committee members' time limitations, we are considering expanding the pool of potential mentors to include all cohort PIs within our community. We will inform you once the new mentors have been assigned to the communities.

Continuing with the community concept, we want to reiterate that the communities' goals are twofold, besides their agenda setting role. Firstly, they serve as forums for sharing knowledge and experiences. Secondly, they aim to establish agreements and standards based on best practices, fostering harmonization among our studies, and improving the potential for future collaboration. The latter goal is particularly important, as it underscores the relevance of these communities.

When we established the communities in the first roadmap, we envisioned them as both concrete and virtual bodies. While significant concrete work has been accomplished, we see potential for strengthening virtual interactions by utilizing Teams channels for connecting, sharing questions and challenges, and exchanging experiences. All communities are invited to further develop this virtual collaboration.

Some communities have requested a budget to cover small out-of-pocket expenses, such as lunch and drinks during gatherings, to support their effort. The Steering Committee intends to approve these requests, providing up to € 1.000 per community per year. Requests for other expenses can be submitted to the ACH program manager.





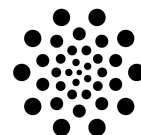
Communities who continue working on concrete tasks are invited to plan their work using the template for action planning for the working groups as presented in Appendix 1 and discuss this with the ACH project manager. This will help you organize your work and identify which capacity is needed and if this is feasible. The ACH project manager is always open to discuss possible bottlenecks in your availability and look for resolutions.

## 5. Our working groups

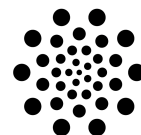
### 5.1 WORKING GROUPS TO BE CONTINUED

In the second phase, we plan to extend four of the seven working groups (and the one subgroup) initiated in November 2023.

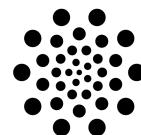
<i>Working group</i>	<i>Follow-up phase 2</i>
1. Machine readable cohort data	<ul style="list-style-type: none"> <li>- In phase 1, the working group worked on standardizing age, fasting glucose and educational level using OMOP, and assigning SNOMED and LOINC codes. The Steering Committee endorses the groups' recommendation to adopt this format for ACH cohorts. The group is invited to continue preparing our cohort studies for FAIRification, beginning with steps to (semi-)automatically generate a demographics table (i.e., Table 1) for individual cohorts and an aggregated table across all cohorts, with the primary aim of enhancing data findability. The group should proceed according to the roadmap outlined in Chapter 5 in its report.</li> <li>- Regarding data dictionaries/codebooks for each cohort study, the working group has the mandate to reach out to cohort studies to discuss their timelines for creating these resources and to monitor this process, with the goal of having the codebooks available by mid-2025. If cohort studies need support in this respect, please flag this to the ACH PMT to see how this can be facilitated.</li> <li>- If the group requires additional guidance from the Steering Committee, they are welcome to submit an interim report, offering options for the next steps along with their pros and cons.</li> <li>- In collaboration with Data Catalogue working group, the group is developing a metadata scheme suitable for cohorts and their data. Both groups are encouraged to continue this collaborative effort, aligning their work with RDM and relevant external initiatives, such as Health-RI, NCC and CHN. The Machine Readable Cohort Data working group focuses on the 'lower level' (variables collected in data sets), while the Data Catalogue working group works on a 'higher level' (cohort data characteristics).</li> <li>- The report does not clearly indicate whether all current group members can continue their commitment. For now,</li> </ul>



		we assume this is the case. If capacity issues arise, please discuss them with the ACH PMT.
2.	Data catalogue	<ul style="list-style-type: none"> <li>- At the Cohort Conference, the working group presented a first demo of a Molgenis-based data catalogue, presenting the ACH cohort studies. This catalogue currently includes general metadata for all our cohorts and more detailed metadata for four studies. Due to legal and technical barriers, selection and retrieval functionalities are not yet feasible.</li> <li>- The group is encouraged to continue completing the data catalogue according to their plan, presenting a general overview of cohort details (not yet at the searchable variable level). As a first step, the group is advised to add a global timeline to their plan, to make it more tangible and trackable.</li> <li>- The positive experiences and fruitful collaboration with Molgenis/UMCG confirm that partnering with them was the right decision. Therefore, the Steering Committee believes that investigating alternatives for the next phase (step 2 of Chapter 5 in the working group's report) is unnecessary. However, if there are issues we have overlooked, we welcome feedback from the group.</li> <li>- For the next steps, the working group has the mandate to discuss with Molgenis/UMCG the conditions under which we can continue using their tool and support. If financial and/or legal agreements are needed, the group's leadership is invited to align these with the ACH PMT.</li> <li>- Regarding the maintenance of the data catalogue, we support the intention to create a plan and SOPs for maintaining the catalogue. This includes reaching out to the cohorts to designate a staff member responsible for maintaining data conditions and technical maintenance, according to these SOPs.</li> <li>- In collaboration with Machine Readable Cohort Data working group, the group is working on a metadata scheme suitable for cohorts and their data. Both groups are invited to continue this collaborative effort, ensuring alignment with RDM and relevant external initiatives, like Health-RI, NCC, and CHN.</li> <li>- The Steering Committee acknowledges the capacity issues raised in the working group's report. We appreciate that most group members intend to stay involved. If the group wishes to invite new members from other cohort studies or the RDM department, they are free to do so. We hope the current chair can continue his efforts for ACH; if not, we suggest contacting the ACH PMT to resolve this issue.</li> </ul>



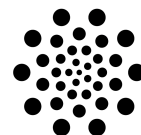
		<ul style="list-style-type: none"> <li>- Regarding necessary resources from other cohorts, we suggest focusing first on completing the catalogue and SOPs for maintenance. We expect this will clarify the ongoing capacity needs. Once the working group has made a global estimate of this requirement, the Steering Committee will discuss how to facilitate these ongoing efforts.</li> </ul>
3.	Linkage	<ul style="list-style-type: none"> <li>- The Steering Committee prioritized identifying and showcasing best practices in linking with external datasets and registries, as raised in the working group's report.</li> <li>- The next step is to design a linkage manual with transparent procedures from the cohort perspective, detailing how to perform linkages with specific registries, associated costs, and how to address GDPR and legal issues in collaboration with LRS and FG.</li> <li>- While the Steering Committee also supports the group's other plans and roadmap, these are considered lower priorities.</li> <li>- The idea of creating an overview of active (or archived) projects within remote access environments (e.g. CBS) and their research questions aligns well with the plan for an ACH knowledge platform and should be included there (see 5.4).</li> <li>- The Steering Committee agrees that bringing new members in this group is essential for fulfilling its tasks. We encourage the group to invite researchers with experience in data linkage or those currently working on it. If finding such expertise within our community proves challenging, the group is welcome to reach out to candidate cohorts.</li> </ul>
4.	Cohort Support	<ul style="list-style-type: none"> <li>- This working group has provided a comprehensive overview of the bottlenecks in the support available to cohorts and initiated talks with support units on these issues, focusing on two clusters: legal and ICT. As a result, two improvement plans are now ready for implementation.</li> <li>- The Steering Committee appreciates the working group's offer to continue overseeing the implementation of these improvement plans and asks them to proceed according to their planning.</li> <li>- As a spin-off, an ACH subgroup developed a plan to improve the relationship between cohorts and the Biobank (and the related CTB). Given the interconnectedness between the legal improvement plan and this advice, it seems appropriate to assign the implementation of the subgroup's plan to the working group as well.</li> <li>- The Steering Committee supports the working group's intention to include a data steward and an RDM staff member. We suggest adding Quint Ollslager to the group and will ask the RDM leadership to assign a staff member to</li> </ul>



	<p>participate. As Research Support/RDM is currently focusing on improving workflows, we expect this participation to create the necessary synergies.</p> <ul style="list-style-type: none"> <li>- Furthermore, Eva Strijbis volunteers to join the group to fill the vacancy created by the transfer of Eva van der Linden and is experienced in dealing with cohort-support functions. Additionally, Natasja van Schoor from the Biobank subgroup has volunteered to participate to ensure continuity on this topic. If the group needs further reinforcement, e.g. on the ICT-topic, it's open to the group to recruit extra members.</li> </ul>
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## 5.2 WORKING GROUP TO BE DECIDED

<i>Working group</i>		<i>Follow-up phase 2</i>
1.	Advanced methodology	<ul style="list-style-type: none"> <li>- Based on surveys assessing the availability and needs for advanced methods expertise, the group developed a GitHub-based website showcasing the different advanced methods expertise available. We view this effort as an excellent foundation for building an ACH knowledge platform. The next step is to integrate this initiative with similar efforts. To achieve this, a new working group will be established to combine these initiatives and select the appropriate platform tools (see 5.4). Participation from one or two members of the this group seems valuable to this new group.</li> <li>- Additionally, the group has proposed a comprehensive plan, first, to create a dynamic researchers' community through tutorials, lab meetings, and workshops, second, to establish a support structure for researchers interested in advanced methodologies for cohort studies through research project collaboration, and third, to develop novel research methodology through regular method-focused meetings.</li> <li>- The Steering Committee fully supports all these initiatives. However, given the significant overlap between these objectives and the goals of the Researchers' community, the Steering Committee invites both groups to discuss potential collaboration or a possible merger.</li> <li>- If there remains a need to continue the Advanced Methodology working group - perhaps in a smaller capacity to finalize the expertise website (step 1 and 2 of the action plan) - this can be determined through discussions and will be supported by the Steering Committee. Our goal is to ensure that the work is carried out efficiently and effectively, without unnecessary duplication.</li> </ul>

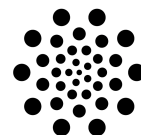


### 5.3 DISCONTINUING WORKING GROUPS

For the remaining working groups from phase 1, the Steering committee intends to build upon their outcomes as follows:

<i>Working group</i>		<i>Follow-up phase 2</i>
1.	Data collection tooling	<ul style="list-style-type: none"> <li>- The group developed an MS Access database that compiles the data collection tooling used in the cognition and mental health domains across six of our cohort studies, highlighting their pros and cons. This overview serves as a valuable starting point for guiding and advising cohort studies when introducing new measurements into their research.</li> <li>- The Steering Committee sees two main challenges for advancing this effort. First, the current database should be expanded to include additional domain and cohort studies not covered in the initial phase. Second, this overview should be integrated into an ACH knowledge platform, making it accessible and navigable for interested users (see 5.4).</li> <li>- For the first task, we intend to follow the working groups' recommendation to invite two members from the group to lead the effort to expand the database with new domains and to develop SOPs for its ongoing maintenance. For this, we suggest to look at the practice of taskforces per domain, as implemented in the Stress-in-Action practice.</li> <li>- For the second task, a dedicated working groups will be formed to develop the ACH knowledge platform, which will unify similar initiatives across multiple working groups (see 5.4.).</li> </ul>
2.	Branding & PR	<ul style="list-style-type: none"> <li>- The group explored the possibilities and limitations of a specific branding strategy and found that opportunities are currently limited. A new visual has been selected to standardize the branding of ACH material, replacing the diverse visuals previously in use. Additionally, the group recommended retaining the ACH name and developed a mock-up for a website. With these tasks completed, the group has fulfilled its assignment and can now be discontinued.</li> <li>- Moving forward, responsibility for branding and communication will shift to the ACH PMT, where a senior communication expert will be recruited.</li> <li>- The Steering Committee emphasizes the importance of supporting cohort studies in their communication efforts and executing the communication plan, along with finalizing the selection of a visual that reflects the unique characteristics of cohort studies.</li> </ul>





		<ul style="list-style-type: none"> <li>- When decisions are made regarding the organizational positioning of ACH, a new working group will be established to develop an ACH website, which will be integrated into the Tulp intranet environment (see 5.5).</li> </ul>
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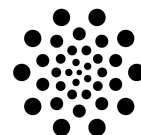
#### 5.4 NEW WORKING GROUPS

One new working group will be installed to leverage the efforts of the communities and working groups from phase 1.

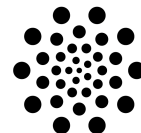
<i>Working group</i>		<i>Goals</i>
1.	ACH-knowledge platform	<ul style="list-style-type: none"> <li>- Several working groups have initiated the creation of provisional databases to share their findings with our community. Others have suggested the need for a centralized location to store information about all cohorts, staff, contact, and even current or archived linkage projects. To build on these initial efforts and meet these needs, we will form a new working group tasked with creating an ACH knowledge platform.</li> <li>- Current databases include Excel files with key cohort parameters, cohort profiles, an overview of study themes, resource across cohorts, data management tools, an Access database for data collection tools, a GitHub website outlining advanced methods expertise, and a BI database with key elements of all cohorts and ACH participants.</li> <li>- We recognize that this is a significant task with the potential to greatly enhance collaboration, quality and efficiency. Therefore, we will form this new working group led by the ACH project manager and composed of staff members with relevant expertise from various cohort studies. Ideally, some members will come from the groups that initiated these databases.</li> <li>- We expect this group to start developing a proof of concept that outlines the challenges and needs this project will address, defines its objectives, identified the tools, resources and efforts required, and established a timeline.</li> <li>- This proof of concept is expected to be completed by the end of 2024, with the entire platform projected to extend until the end of 2025.</li> </ul>

#### 5.5 FUTURE WORKING GROUPS

The future working groups will not be installed September 2024, but later in 2025 or when the prerequisites for these groups are met.



<i>Working group</i>		<i>Goals</i>
1.	Annual Cohort Conference Amsterdam 2025	<ul style="list-style-type: none"> <li>- Following the successful first cohort conference organized by the Coordination community and facilitated by APH staff, we plan to install a new team of ACH participants to prepare for the 2025 conference, as recommended by the Coordinators' community. The start of this group is envisioned early 2025.</li> <li>- We are seeking a diverse group of colleagues representing all disciplines, with additional operational expertise in organizing conferences.</li> <li>- To build on the experience of the first organizing committee, it may be beneficial to include a member from that team in the new group.</li> <li>- The Coordinators' community's evaluation from the first conference will be shared with this new team to assist in planning the upcoming event. The Steering Committee unanimously viewed the conference as a success and supports making it an annual event. We suggest also inviting data experts as keynote speakers, alongside researchers.</li> </ul>
2.	Building an ACH-website	<ul style="list-style-type: none"> <li>- The new ACH website will be designed to fulfill multiple purposes. Initially, we anticipate the website will focus on two key objectives:               <ol style="list-style-type: none"> <li>1. Supporting researchers and facilitating collaboration:                   <ol style="list-style-type: none"> <li>a. Integrating our comprehensive overview of all ACH cohorts;</li> <li>b. Incorporating the data catalogue with detailed information on participants, study waves, and measured domains within ACH cohorts;</li> <li>c. Providing access to the repository of expertise on advanced methodologies.</li> </ol> </li> <li>2. Sharing knowledge and best practices with new cohorts:                   <ol style="list-style-type: none"> <li>a. Integrating our knowledge platform as developed by the working group ACH-knowledge platform (see 3.2.4.).</li> </ol> </li> </ol> </li> <li>- A dedicated future working group will be established to oversee the website's development once the positioning of ACH within Amsterdam UMC is confirmed.</li> <li>- This group will include our senior communication expert, ACH community members experienced in website development, and possibly ICT professionals, depending on the needs.</li> </ul>



## 5.6 POSITIONING

The descriptions provided for each working group are intended as outlines of their purpose, goals, and activities. While we've aimed to be as concrete as possible, the ACH PMT is available to clarify any questions regarding each group's objectives. Each group is responsible for developing its own action plan to achieve these goals and manage their work, with a template provided in Appendix 1. The time horizon of this roadmap is December 2025, but of course, groups are welcome to report their results or midterm results to the Steering committee earlier, if possible or at their convenience. Groups are expected to share and discuss their action plans with the ACH project manager.

For the composition of the working groups, we anticipate that most existing groups will remain largely unchanged. Groups that need additional capacity or expertise are encouraged to recruit new members from within our cohort community and support functions. We expect candidates to consult with their supervisors before joining any group. For the staffing of new groups, the ACH project manager will issue a call for volunteers who are inspired by the topic and wish to contribute. The first opportunity to express interest will be at the Reconnect meeting on September 3.

As in the first phase, we ask all groups to choose a chair and a chair-support to organize the groups' work processes and represent them within ACH. The ACH project manager will organize regular coordination meetings with them to align the groups' work and connect the chairs and chair-supports, as in the previous ACH-phase.

## 5.7 CAPACITY PLANNING

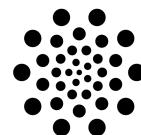
With this new roadmap we largely follow the recommendations of the working groups and community from phase 1. Still, we realize the available capacity and capacity planning is always an issue to fulfill our ambitions, regardless the facilitation of our project by the sectorgelden. As the Steering Committee nor the ACH PMT can clearly estimate which efforts are needed for each working group, we want to invite all groups to present us their estimations using sections 8 in the template action plan, Appendix 1. And please, flag capacity issues that are expected in this respect to the ACH project manager, to see how these can be solved or managed. If needed, the Steering Committee is open to review its priorities, based on the capacity available instead of our collective ambition, now prevalent throughout this roadmap.

For now, no out of pocket-budget is reserved for the working groups, as we didn't receive any of those requests. Working groups expecting to need a budget to cover operational, material or licensee costs, are invited to flag these in section 9 of the template and discuss these with the ACH project manager.

# 6. Supplementary actions

## 6.1 EXPLORATORY ACTIONS

The Steering Committee intends to start an exploratory phase on two topics to see how we can jointly develop these. The ACH PMT will lead these exploratory actions and invite



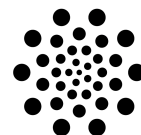
others to join this effort. We will decide whether more formal working groups are needed based on these results.

1.	Stretching the grant pipeline	<ul style="list-style-type: none"> <li>- As ACH aims to contribute to the sustainability of our cohort studies, expanding our grant pipeline and increasing our grant possibilities for research, talent development and infrastructure is a priority for our community.</li> <li>- In collaboration with the Grant Support Office, we aim to create a more structured infrastructure for managing and monitoring grant efforts within our network and to systematically identify new opportunities for grant applications.</li> <li>- To achieve this, in partnership with the Grant Support Office the ACH PMT together with some of our community members will explore or a more systematic process for identifying grant opportunities, managing applications, and monitoring progress is apposite and how such a process could look like.</li> </ul>
2.	Leveraging valorization and impact	<ul style="list-style-type: none"> <li>- As highlighted by the Coordinators' community, there is significant potential to improve the transfer of our knowledge to society. Together with IXA, we also see opportunities to enhance our business development efforts and better utilize our data, contributing to our reputation, impact and revenue streams.</li> <li>- To explore these opportunities, together with IXA and some of our community members the ACH PMT will investigate how to leverage our knowledge and data for maximum impact and revenue, and thus stretching the Coordinators' community's efforts on knowledge transfer.</li> </ul>

## 6.2 DELEGATED TO THE ACH PMT

Following up on the efforts of the Data stewards' community on the role and responsibilities of cohort-specific data stewards needs dedicated advocacy towards the HR-domain of the Amsterdam UMC. We see the ACH leadership as the most eligible party to pursue this.

1.	Professionalization Data stewardship	<ul style="list-style-type: none"> <li>- Building on the work of the Data stewards' community, which clarified the roles and responsibilities of data stewards within the cohort context, we ask the ACH PMT to foster these efforts. Given the unique challenges faced by data stewards in cohort research, we agree with the community that a dedicated attention is necessary to further professionalize ACH data stewardship.</li> <li>- The ACH PMT is asked to follow up on the action plan initiated by the community, including providing recommendations on the positioning and responsibilities of ACH data stewards, developing competency descriptions,</li> </ul>
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		and creating a training and professionalization track specific to cohort studies, in collaboration with HR and RDM, working on data stewards' professionalization too.
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## 7. Matching groups, actions and mission

To ensure our initiatives align with the mission and goals of our network, we have mapped the communities and working groups to ACH's areas of action in the table below (table 1).

		1. Active Network	2. Data infrastr.	3. Cohort support	4. Reuse of data	5. Lobby & PR	6. Partner-ships
C1	Fieldworkers	X		X			
C2*	Data stewards	X					
C3*	Data managers	X	X				
C4	Coordinators	X					
C5	Researchers	X			X		
W1	Machine readable cohort data		X		X		
W2	Data catalogue		X		X		X
W3	Linkage		X		X		
W4	Cohort support			X			
(W5)	(Advanced methods)**			(X)			
W6	Knowledge platform	X		X			
<i>Further (prospective) actions</i>							
A	Cohort conference 2025	X				X	X
B	ACH Website	X			X	X	X
C	Grant pipeline			X		X	X
D	Valorization and impact			X	X		X
E	Professionalization data stewardship			X	X		

\* groups might merge, to be decided in mutual consultation by both groups

\*\* might merge into the Researchers' community, to be decided in mutual consultation by both groups

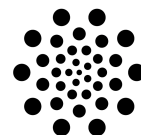
*Table 1: Communities, working groups and ACH's areas of action*

As this table shows, all communities and working groups contribute to at least one of the areas of action derived from our mission. At the same time, all areas of action are served by our communities and working groups. Especially the fields lobby & pr and partnerships will additionally be served by the advocacy activities by the ACH-director. Thus, we can conclude that with this roadmap good next steps are taken to bring the mission of ACH further to life.

## 8. ACH-candidates

Over the past months, quite some cohort studies showed interest in joining our coalition of cohort studies, which we now call cohort candidates (table 2).





100-plus study (100+ elderly without dementia)	COHoRT (evaluation lifestyle programs)
ENIGI (transgender cohort)	Generation2 (mental health pregnant women and parents)
InterRAI (nursing home care)	NAR (autism)
NMCB (sleep/fatigue disorders)	OMEGA (ART, mother-cohort, child-cohort)
Sanquin several studies (DIS, FIND'EM, FORTE(research into blood donors), Escalation (early cancer detection), Future Health (decease projection), EIRENE (exposure assessment) en LBC (liquid biopsy collection)	Sarphati (children Amsterdam)
In Kaart (neurodiverse persons and their parents or caregivers)	NOVICE (children born with HIV)
Amsterdamse Cohort Studies (GGD HIV/MSM)	Longitudinal cohort in gynecological oncology

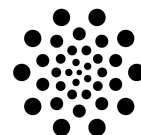
*Table 2: ACH-candidates August 2024*

To assess the fit between these cohort studies and the objectives of ACH, the steering committee is working on a set of acceptance criteria and an accompanying procedure. As soon as these are set, we can start inviting new studies into our community. This will probably be early Autumn 2024. The cohort candidates are informed about this planning and process.

As soon as a study is welcomed within our community, we will invite them to join our communities and working groups, in alignment to their available resources and capacities. Thus, the composition of our communities and working groups can grow over the coming planning period. As we are working with a longer time horizon now, we think adopting new participants into these groups is workable, and even desired, given the efforts and capacities needed to properly execute this new roadmap. Of course, the ACH project manager will discuss with each individual community and working group the conditions for introducing new members. This also applies to the influx of new cohorts later in time.

## 9. Overall monitoring

This draft roadmap is now available for discussion during our Reconnect event on September 3. Subsequently it will be discussed for the second time in our Steering committee and presented to our Advisory Board. Afterwards it will be finalized. The overall monitoring and management of the roadmap is handed over to the ACH PMT.



## Appendix 1: Template action plan working groups ACH

1.	Name working group			
2.	Participants	Please list all involved, with the cohort they represent		
3.	Chair	Which team member will act as chair		
4.	Chair support	Which team member will act as chair-support		
5.	Goals	Formulate the goals of the group as concrete as possible, derived from the roadmap.		
6.	Deliverable	Formulate the deliverables the working group intends to produce.		
List below the steps the group intends to undertake to come to these deliverables, with their intended result and planning. Extend or copy this part of the format if needed. Listing steps per deliverable is advised.				
7.	Step	What	Result	When
	1.			
	2.			
	3.			
	4.			
	5.			
8.	Resources working group	Map which capacity per working group member is needed per week or per month to participate in this working group. Express per member, if this is feasible or if bottlenecks are expected.		
9.	Other resources	Map which other resources are needed for this working group. Think about material resources and human resources from other studies or departments.		
10.	Budget	Which budget does the working group need for the execution of their plan		
11.	Reports	When and how will the group report to the ACH project management team and Steering committee		
List below the risks the working group envisions and how it plans to mitigate these risks				
12.	Risks	Risk mitigation		
	1.			
	2.			
	3.			
13.	Collaboration	Describe with which other groups, communities or departments the working group anticipates collaboration and how it plans to organize this.		