

## NEOLAIA Focus Academy

### Course Syllabus

#### Personal Health Data Management

##### Instructors

**Assign local academic coordinators from each participating university to lead the course, ensuring diverse expertise and perspectives.**

University of Salerno (coordinator), University of Nicosia (co-organizer), University of Örebro (co-organizer), Šiauliai State University of Applied Sciences (co-organizer)

Bice Della Piana, UNISA, Italy  
 Christiancarmine Esposito, UNISA, Italy  
 Despo Ierdiakonou, UNIC, Cyprus  
 Shang Gao, ORU, Sweden  
 Panagiota Chatzipetrou, ORU, Sweden  
 Rasa Pocevičienė, SVK, Lithuania  
 Eslanda Mockevičienė, SVK, Lithuania  
 Vilija Vaikasiene, SVK, Lithuania

##### Overview and general data

**Provide a brief overview of the course, highlighting its relevance to the NEOLAIA Pillars and the collaborative nature of the course development process.**

The proposed Focus Academy on Personal Health Data Management aims to equip participants with comprehensive knowledge and skills in the collection, processing, visualization and management of personal healthcare data using ICT technologies, aligning with NEOLAIA's first pillar, Digital Transformation [Pillar 1-NP1) Digital Transformation]. The course will be specifically focused on ICT tools, user engagement strategies to enhance the adoption and effectiveness of digital health solutions, and addresses security and privacy concerns, ensuring compliance with legal and ethical frameworks. The course will explore the set of standard and data modelling techniques coming from the HL7 organization (Begoyan, 2007): introduction to the FHIR data model and exchange, data profiling and implementation of a data repository. In addition, the topic of data lifecycle model (El Arass et al., 2018; Shah et al., 2021) will be presented and its application to healthcare data will be discussed. An additional focus will be on the concept of stakeholder engagement (Kujala et al., 2022; Quanbeck, 2019; Lo Presti et al., 2019; Boaz et al., 2018; Ray and Miller, 2017; Lavalley et al., 2014) and the most used methods to measure it (Dukhanin et al., 2023; Martinez et al., 2019; Concannon et al., 2014). Last, healthcare data is an example of personal data and subject to the obligations and protections expressed in the latest normative tools making the EU framework for data protection, such as GDPR. This course will also highlight the rights of citizens when handling their healthcare data and the required technical and organization measures to preserve the privacy and security when handling such sensitive data. This interactive and interdisciplinary course involves different academic institutions, healthcare professionals, technology and management experts, making the program essential for those aiming to lead in the digital health domain by integrating theoretical knowledge with practical applications and ethical considerations. The main theoretical reference will be the Human-centered approach (Bingley et al., 2023; Bazzano et al., 2017; Melles et al., 2020).

## Objectives

**Clearly define the objective(s) of the course (at least five).**

1. Provide training on ICT technologies for the collection, processing, and visualization of personal healthcare data.
2. Modelling data lifecycle of healthcare data: best practices and issues.
3. Develop strategies to make digital health solutions attractive and effective.
4. Introduce participants to the security and privacy concerns mandated by legal frameworks and ethical guidelines.
5. Offer hands-on experience bridging the gap between theoretical knowledge and practical application.
6. Encourage collaboration among academic institutions, healthcare professionals, and technology and management experts to address challenges in the digital transformation of healthcare.

## Learning outcomes and competencies

**Outline the specific learning outcomes and competencies that students are expected to acquire upon completion of the course, aligning with the duration and ECTS requirements.**

The Focus Academy will allow participants to have hands-on experiences on the way to properly manage, process and secure healthcare data as well as making the digital services usable and privacy-preserving. The set of competences will include aspects from computer science, managerial engineering as well as privacy law. The obtained competences will be assessed through our a project jointly conducted by pairs of participants on specific aspects of digitalization of healthcare data, effective and efficient handling of data during their lifecycle, and stakeholder engagement in digital services for healthcare.

## Contents

**Define the scope and content of the course, including key topics, themes, and concepts to be covered.**

The topics covered by the Focus Academy are transversal and interdisciplinary: instructors will have a diverse background from Computer Science and ICT Technologies, Privacy and Law, Management Engineering. Such transversal domain is proved by the involvement of more than one department. This will provide a cross-sectoral training to the participants.

## Number of students, profile, selection process, and registration

**Specify the number of students to be enrolled in the course, along with their desired recommended profile and suggestions for the selection criteria (they have to be homogeneous to be applied by each institution sending students). Provide guidance on the registration process for students from participating universities.**

The BIP will include a maximum of 20 students for the physical mobility component, with each partner university nominating up to 5 participants. For the virtual mobility component, the program can accommodate up to 90 students, ensuring broad participation across institutions.

The student profile is intentionally diverse, including individuals from fields such as computing, health sciences, computer science, and medicine. While the majority of participants are expected to be bachelor's students, there may also be some master's students, reflecting the interdisciplinary nature of the program and its focus on bridging technical and healthcare expertise. The selection

process for participants is managed internally by each partner university, following their own established procedures and timelines. Nomination deadlines are generally set between March and April. Once the students have been selected, the universities will provide UNISA with a finalized list of participants. UNISA will then handle the enrollment process, ensuring that all nominated students are registered for both the virtual and physical components of the program.

## Activities

**Design a variety of synchronous and asynchronous activities to engage students in both large cohorts and small groups. Indicate which activities will be open to the wider community and to which sectors (students; staff; faculty; wider society). Incorporate opportunities for collaborative learning, discussions, and hands-on exercises.**

During the virtual mobility phase, the learning process will revolve around modular topics. The asynchronous aspect of the program includes the provision of pre-recorded videos and carefully selected articles, which will be uploaded to the academy platform. Participants will study these materials independently, fostering self-paced learning. Each module will conclude with a synchronous session held on Microsoft Teams, providing an opportunity for real-time interaction. These live sessions will include Q&A discussions, where students can address their doubts and curiosities, and instructors will elaborate on key points and present additional material. To extend the impact of the virtual component and engage a broader audience, the program will conclude with an open seminar featuring an external expert. This event will be accessible to the wider academic and professional community, including students, staff, and faculty from partner universities.

The physical mobility component will span five days of immersive learning and interaction, with each day comprising eight hours of activities. This in-person phase will include a mix of seminars and hands-on project activities. Participants will collaborate to develop practical outputs, such as a comprehensive data management plan, allowing them to apply theoretical knowledge in a real-world context. In addition to the academic focus, the program also emphasizes cultural exchange and social interaction with the opportunity to visit iconic locations such as Pompei or the Amalfi Coast.

## Calendar/program

**Develop a detailed calendar or program outlining the schedule of activities, including virtual sessions, physical mobility periods, and individual work assignments. Indicate which activities will be open to the wider community and to which sectors (students; staff; faculty; wider society).**

<b>Virtual Component</b>	9-20 June 2025	<ul style="list-style-type: none"> <li>Asynchronous pre-recorded videos and curated articles on the academy platform. Participants study materials independently at their own pace.</li> <li>Synchronous session on Microsoft Teams for Q&amp;A discussions. Instructors elaborate on key points and present additional materials.</li> <li>Open seminar featuring an external expert on a relevant topic.</li> </ul>
<b>Physical Component</b>	30 June – 4 July	<ul style="list-style-type: none"> <li>Seminars on core topics related to health data management and hands-on project work in international teams, focusing on developing a comprehensive data management plan.</li> <li>Cultural and social activities, promoting cultural exchange and networking.</li> </ul>

		<ul style="list-style-type: none"> <li>Finalization of project outputs and project presentations by teams, followed by Q&amp;A sessions. Closing seminar and reflective discussions.</li> </ul>
<b>Assessment</b>		
<p><b>Define the assessment methods and criteria used to evaluate student performance, ensuring alignment with the learning outcomes and competencies. Consider a mix of formative and summative assessments to provide holistic feedback to students.</b></p> <p>Students will work on projects addressing real-world case studies of technological platforms managing personal health data. Formative feedback will be provided throughout the process to refine their work and enhance their understanding. The summative assessment will take place at the end of the physical mobility phase, where international and multi-sectorial teams will present their projects through slides and respond to questions. Evaluation will focus on project content, presentation quality, and the ability to address questions, ensuring a comprehensive measure of student performance.</p>		
<b>Additional comments</b>		
<p><b>This section is to provide any other relevant information that does not fit within the previous sections.</b></p>		
<b>References</b>		
<p><b>Add relevant references, the reading list, and other learning resources.</b></p> <p>Bazzano, A. N., Martin, J., Hicks, E., Faughnan, M., &amp; Murphy, L. (2017). Human-centred design in global health: A scoping review of applications and contexts. <i>PLOS ONE</i>, 12(11), 1–24. <a href="https://doi.org/10.1371/journal.pone.0186744">https://doi.org/10.1371/journal.pone.0186744</a></p> <p>Begoyan, A. "An overview of interoperability standards for electronic health records." <i>USA: society for design and process science</i> (2007). <a href="https://citeseerx.ist.psu.edu/document?repid=rep1&amp;type=pdf&amp;doi=5ca532439868b9fac13bf5a0d6b46365280828d3">https://citeseerx.ist.psu.edu/document?repid=rep1&amp;type=pdf&amp;doi=5ca532439868b9fac13bf5a0d6b46365280828d3</a></p> <p>Bingley, W. J., Curtis, C., Lockey, S., Bialkowski, A., Gillespie, N., Haslam, S. A., Ko, R. K. L., Steffens, N., Wiles, J., &amp; Worthy, P. (2023). Where is the human in human-centered AI? Insights from developer priorities and user experiences. <i>Computers in Human Behavior</i>, 141, 107617. <a href="https://doi.org/10.1016/j.chb.2022.107617">https://doi.org/10.1016/j.chb.2022.107617</a></p> <p>Boaz, A., Hanney, S., Borst, R., O'Shea, A., &amp; Kok, M. (2018). How to engage stakeholders in research: Design principles to support improvement. <i>Health Research Policy and Systems</i>, 16(1), 60. <a href="https://doi.org/10.1186/s12961-018-0337-6">https://doi.org/10.1186/s12961-018-0337-6</a></p> <p>Concannon, T. W., Fuster, M., Saunders, T., Patel, K., Wong, J. B., Leslie, L. K., &amp; Lau, J. (2014). A Systematic Review of Stakeholder Engagement in Comparative Effectiveness and Patient-Centered Outcomes Research. <i>Journal of General Internal Medicine</i>, 29(12), 1692–1701. <a href="https://doi.org/10.1007/s11606-014-2878-x">https://doi.org/10.1007/s11606-014-2878-x</a></p> <p>Dukhanin, V., Wolff, J. L., Salmi, L., Harcourt, K., Wachenheim, D., Byock, I., Gonzales, M. J., Niehus, D., Parshley, M., Reay, C., Epstein, S., Mohile, S., Farrell, T. W., Supiano, M. A., Jajodia, A., &amp; DesRoches, C. M. (2023). Co-Designing an Initiative to Increase Shared Access to Older Adults' Patient Portals: Stakeholder Engagement. <i>J Med Internet Res</i>, 25, e46146. <a href="https://doi.org/10.2196/46146">https://doi.org/10.2196/46146</a></p>		

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