

945345 – H2O

Health Outcomes Observatory

WP6 – WP Observatory management- communications and analysis

D6.4 Repository of use cases of the Observatories

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Document History

Version	Date	Description
V1.0	22/07/2021	First Draft outline
V1.1	21/08/2021	Comments
V1.2	24/08/2021	Draft, comments, additional input outline
V2.0	07/09/2021	Review for country leads
V2.1	13/09/2021	Internal review
		Final Version

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Abbreviations

Acronym / Ab- breviation	Meaning
NO	National Observatory
WP	Work package
PRO	Patient reported outcome
CRO	Clinical reported Outcomes
RWD	Real World Data
EMR	Electronic medical record
D	Deliverable
IBD	Inflammatory Bowl Disease
HCP	for Health Care Providers

Abstract

This deliverable outlines the potential multipurpose value of the H2O National Observatory (NO). The purpose of this document is to make an inventory of use cases, in order to show what value the NOs could bring. For example; how the H2O NO might create value for patients, healthcare providers, private sector and to the society. This will lead to examples to show the range of practical implications and promote their adoption. We aim to do this in two ways; 1) by choosing existing use cases that have a strong basis and longer existence with a broader patient population in a country, 2) by making assumptions and placing questions that are still unanswered on a disease population level. The latter exercise will be continued after submitting the deliverable. In order to compare the use cases in the different countries, identify strong assets in knowledge and geographic coverage and eventual gaps, we will follow up the developments in the countries on the use cases with a working group from this deliverable's group. It will take more time to analyse all use cases and create insights which questions have been answered and which ones still needs effort to answer.

We will challenge the H2O ambitions by questioning each use case on the following six items; outcomes, patient satisfaction and communication, improve science, faster science, innovate health policy, costs or financing. First of all we will apply the questions to the existing use case(s), secondly we will place the assumptions that will show the multipurpose value of the H2O NO. Those questions will be answered based on the available data or research of the existing use case. This information will help us to make assumptions on the improvements that are still needed in healthcare. This will also create the value propositions for the H2O NOs.

There is a strong relationship with the data management plans from WP1 and 2, but also with theoretical use cases described in the feasibility plans. It is of practical value to use a generic description of the use cases and to start with already existing use cases. These use cases can then be discussed and analyzed in order to develop a more generic blueprint. In this way, this will then be part of a continuous learning process.

1. Impact

H2O aims to make an impact on future healthcare. To clarify the why behind the initiatives within H2O and create an understanding for all collaborators within H2O and abroad we have defined six areas where an impact might be made. We have placed questions that might not be answered yet on a disease population level or not in all cases that H2O aims to adopt. Therefore, we challenge the H2O initiative by asking the following questions on six items where impact can be made. For each use case the questions will be sent to the initiators to be filled out, this process will help the H2O NOs to identify strong cases, gaps and learning opportunities. In case the questions couldn't be answered with the current use case, then we will consider these questions for the future use cases. The information collected will help clarify what value several initiatives have been creating so far, whether or not they were meaningful to patients, clinicians or society. Building on these answers we will try to improve the H2O NO use cases, adapt the ambitions and value proposition for the H2O NOs. The information collected from these answers will also be used as a degree of implementation of new insights.

1. Outcomes

- a. Has the example/ use case led to improvement of the quality of life of patients? If yes, please specify.

Examples could be:

- i. influence patient's survival?
 - ii. Were PRO's and medical outcomes/ Clinical outcome measurements (CRO's) enabled to lead to better patient outcomes, if yes how?
 - iii. Was hospital stay – if applicable- influenced, shortened?
- b. What have we learned so far specifically from this use case?
 - c. Have lessons been learned applicable for H2O NO?

2. Patient satisfaction and communication

- a. Were patients asked for their satisfaction with the care process?
- b. Were patients empowered/ enabled to improve conversations with doctors?
- c. Have the results shown that patient satisfaction increased?
- d. Have the results shown that patient communication improved?
- e. How can value be added to patient empowerment, education, and experience?

3. Improve science

- a. Which research questions were answered (any publications available?)
 - i. Were all questions answered? With which degree of confidence?
- b. Which unanswered questions were envisioned that should be answered within H2O?
- c. Has this data/ research been opened to society, public and private sector (any link available?)?
- d. Are there suggestions on innovative ways of science applying existing data/ Real World Data (RWD)?

4. Faster science, reduce burden

- a. Can we reduce the burden on patients by using patient-reported data in control arms of clinical trials?
- b. Can we create real reliable and meaningful world evidence?
- c. Can we use various types of RWD (eg. EMR data) as control arm for clinical trials??

5. Innovate Health policy

- a. Have the learnings from the use case(s) contributed to new health policy?
- b. How can H2O contribute to changes in health policy?

6. Costs/ financing

- a. How can the available data be used for better utilization of resources?
- b. How can we improve/ fasten the process of outcome-based payment models with industry?
 - i. What else needs to be done/ what data/ research is needed to prove whether a treatment has worked?
- c. How can we facilitate the national healthcare systems with access to data, to transform from volume-based to value-based care delivery?

2. Current Use cases

To create insight into the current status of the diseases in the project, in the different countries following the outcome-based healthcare, we have collected the use cases of the four tier one countries. The results are shown in the table below. At a later stage more countries will be included to the H2O initiative.

Country	Diseases/ cases					
	Breast Cancer	Diabetes	IBD	Non-Small cell Lung cancer	Generic PROs	others
Austria	x	x	Under development	Under development	Under development	
Germany	x	x			Under development	
Spain	x	x	x	xxxx	Under development	
The Netherlands	x	x	xx	Under development	Under development	

Figure 1. overview of the current use cases in different countries.

X: number of use cases/ projects in the same disease area

3. Future Use Cases

This deliverable will continue working on this topic after submission to the IMI. The H2O team will

analyse these use cases and compare the results of the countries. After the analysis choices need to be made on which use case will be included first in the H2O NO to be benchmarked. Besides the three disease areas other diseases and generic PROs will be considered to be included in the H2O NO. In addition a continuous learning process will be set up within the national observatories to learn from each other across Europe.

4. Annex 1 Template Use cases

1.1.1.D6.4 Repository of use cases

The purpose of this document is to make an inventory of use cases, to create insights in the progress of the patient reported outcome (PRO) initiatives over the countries participating in the H2O project. This will help to test the value of the NO discover the possible value propositions for the NO. Therefore, we have composed a template to create insights into the different use cases over the four tier one countries, starting with diabetes, IBD and oncology breast cancer. There was no selection procedure for these use cases. The tier one countries were asked to provide use cases at least for the three diseases areas within the H2O project. More use cases were allowed for inclusion in the deliverable.

1.1.2. Empty Template for Countries H2O use case

H2O template country use cases diseases	
Country	
Disease	
Objective of the initiative	
Timeline	
Collaboration with other hospitals/ nursing homes/ ...?	
Outcome set(s) used	
Which Provider reported data are collected?	
Do data originate from the EMR? Registries? Both?	
Which Patient Reported Outcome Measures (PROMs) used?	
Paper based or digital PROM collection?	
Data dictionary available?	
International standard(s) (e.g. SNOMED CT, LOINC or other international standards)	
Common data model used?	
Name of data capture tool, purchased or developed?	

Dashboard for patients available?	
Dashboard for Health Care Providers (HCP) available?	
Name Platform Provider if available	
Any benchmarking?	
Literature references available from research group?	

2. The Netherlands Breast cancer

H2O template country use cases diseases Organization of quality indicators, breast cancer NL	
Country	The Netherlands
Disease	Breast cancer
Objective of the initiative	The best possible, state-of-the-art treatment for every patient with cancer, now and in the future” The development of a regional platform and dashboard for breast cancer
Timeline	
Collaboration with other hospitals/ nursing homes/ ...?	9 hospitals within the South West of The Netherlands (amongst which 1 academic center), Albert Schweitzer, Ikazia, Amphia, Erasmus MC, Franciscus gasthuis & Vlietland, Maasstad, Spijkenisse Medisch Centrum, Van Weel Bethesda, CCN Zuidwest Nederland (funded by Citrefonds)
Outcome set(s) used	Standard set Breast Cancer ICHOM; a combination of Patient Reported and Provider Reported outcomes ¹ (for future initiative the H2O outcome set will be used) ¹ Ong WL, Schouwenburg MG, van Bommel ACM, Stowell C, Allison KH, Benn KE, Browne JP, Cooter RD, Delaney GP, Duhoux FP, Ganz PA, Hancock P, Jaggi R, Knaul FM, Knip AM, Koppert LB, Kuerer HM, McLaughlin S, Mureau MAM, Partridge AH, Reid DP, Sheeran L, Smith TJ, Stoutjesdijk MJ, Vrancken Peeters MJTFD, Wengström Y, Yip CH, Saunders C. A Standard Set of Value-Based Patient-Centered Outcomes for Breast Cancer: The International Consortium for Health Outcomes Measurement (ICHOM) Initiative. JAMA Oncol. 2017 May 1;3(5):677-685. IF 16.65 Q1 Medicine; Top 10
Which Provider reported data are collected?	See ‘data dictionary’ and ICHOM publication
Do data originate from the EMR? Registries? Both?	EMR as well as registry Integraal Kankercentrum Nederland (IKNL)
Which Patient Reported Outcome Measures (PROMs)	Yes, 1. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire: EORTC QLQ-C30 . 2. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire: EORTC QLQ-BR23 3. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire: EORTC QLQ-LMC21 4. BREAST-Q Patient Reported Outcomes Instrument: BREAST-Q 5. Functional Assessment of Cancer Therapy Endocrine Subscale: FACT-ES (6. EQ-5D5L as extra in the academic center)
Paper based or digital PROM collection?	Digital (every hospital has their own data capture tool; 1 platform being Dutch Hospital Data (DHD))

Data dictionary	Available (will be attached later), following Dutch Health Information building blocks (ZIBs), using Value sets
International standard(s) (fe SNOMED CT, LOINC or other international standards)	LOINC/ SNOWMED
Common data model used?	Yes, will be developed for EORTC PROM data
Name of data capture tool, purchased or developed?	Gems Tracker / Brightfish / PROFILES... (differs between hospitals)
Dashboard for patients available? Name?	Yes
Dashboard for HCP available?	Yes
Name Platform Provider if available	Duth Hospital Data (DHD)
Any benchmarking?	Yes, 4 times a year HCPs and managers gather to have a look at the data
Literature references available from research group?	<p><u>References on use of PROMs in breast cancer and quality of breast cancer care of the Erasmus MC research group:</u></p> <ul style="list-style-type: none"> -Lagendijk M, van Egdom LSE, van Veen FEE, Vos EL, Mureau MAM, van Leeuwen N, Hazelzet JA, Lingsma HF, Koppert LB. Patient-Reported Outcome Measures May Add Value in Breast Cancer Surgery. <i>Ann Surg Oncol</i>. 2018 Nov;25(12):3563-3571. -van Egdom LSE, Lagendijk M, van der Kemp MH, van Dam JH, Mureau MAM, Hazelzet JA, Koppert LB. Implementation of Value Based Breast Cancer Care. <i>Eur J Surg Oncol</i>. 2019 Jan 4. - van Egdom LSE, Hazelzet JA, Koppert LB. <u>Reply to: Moving forward with value-based healthcare: The need for a scientific approach.</u> <i>Eur J Surg Oncol</i>. 2019 Jul;45(7):1300. - van Egdom LSE, Pusic A, Verhoef C, Hazelzet JA, Koppert LB. <u>Machine learning with PROs in breast cancer surgery: caution: Collecting PROs at baseline is crucial.</u> <i>Breast J</i>. 2020 Jun;26(6):1213-1215. - van Egdom LSE, Oemrawsingh A, Verweij LM, Lingsma HF, Koppert LB, Verhoef C, Klazinga NS, Hazelzet JA. <u>Implementing Patient-Reported Outcome Measures in Clinical Breast Cancer Care: A Systematic Review.</u> <i>Value Health</i>. 2019 Oct;22(10):1197-1226. -Lagendijk M, van Egdom LSE, Richel C, van Leeuwen N, Verhoef C, Lingsma HF, Koppert LB. Patient reported outcome measures in breast cancer patients. <i>Eur J Surg Oncol</i>. 2018 Jul;44(7):963-968. - de Ligt KM, van Egdom LSE, Koppert LB, Siesling S, van Til JA. <u>Opportunities for personalised follow-up care among patients with breast cancer: A scoping review to identify preference-sensitive decisions.</u> <i>Eur J Cancer Care (Engl)</i>. 2019 May;28(3):e13092. - van Egdom LSE, de Kock MA, Apon I, Mureau MAM, Verhoef C, Hazelzet JA, Koppert LB. Patient-Reported Outcome Measures may optimize shared decision-making for cancer risk management in BRCA mutation carriers. <i>Breast Cancer</i>. 2020 May;27(3):426-434. -van Verschuer VMT, Mureau MAM, Heemskerk-Gerritsen BAM, Gadradj PS, Rogier C, Verhoef C, Gopie JP, Seynaeve C, Koppert LB. Long-term outcomes of bilateral direct-to-implant breast reconstruction in women at high breast cancer risk. <i>J Plast Surg Hand Surg</i>. 2018 Aug;52(4):245-252. - Vos E, Koppert L, van Lankeren W, Verhoef C, Koerkamp BG, Hunink M. A preliminary prediction model for potentially guiding patient choices between breast conserving surgery and mastectomy in early breast cancer patients; a Dutch experience. <i>Qual Life Res</i>. 2018 Feb;27(2):545-553.

	<p>- Lagendijk M, Vos EL, Nieboer D, Verhoef C, Corten EML, Koppert LB. Evaluation of cosmetic outcome following breast-conserving therapy in trials: panel versus digitalized analysis and the role of PROMs.</p> <p>- Lagendijk M, Vos EL, Koning AHJ, Hunink MGM, Pignol JP, Corten EML, de Monye C, van Deurzen CHM, van Dam JH, Vrijland WW, Contant CME, Verhoef C, van Lankeren W, Koppert LB. Tumor-volume to breast-volume RAtio for improving COSmetic results in breast cancer patients (TURACOS); a randomized controlled trial. BMC Cancer. 2017 May 17;17(1):336.</p> <p>- Vos EL, Koning AH, Obdeijn IM, van Verschuer VM, Verhoef C, van der Spek PJ, Menke-Pluijmers MB, Koppert LB. Preoperative prediction of cosmetic results in breast conserving surgery. J Surg Oncol. 2015 Feb;111(2):178-84.</p> <p>- Vos EL, Lingsma HF, Jager A, Schreuder K, Spronk P, Vrancken Peeters MTFD, Siesling S, Koppert LB. Effect of Case-Mix and Random Variation on Breast Cancer Care Quality Indicators and Their Rankability. Value Health. 2020 Sep;23(9):1191-1199.</p> <p>- Vos EL, Koppert LB, Jager A, Vrancken Peeters MTFD, Siesling S, Lingsma HF. From Multiple Quality Indicators of Breast Cancer Care Toward Hospital Variation of a Summary Measure. Value Health. 2020 Sep;23(9):1200-1209.</p> <p>-Clarijs ME, Thurell J, Kuehn F, Uyl-de Groot CA, Hedayati E, Karsten MM, Jager A, Koppert LB. Measuring Quality of Life using Patient-Reported Outcomes in Real-World Mestastatic Breast Cancer Patients: the need for a standardized approach. Cancers. 2021 May; 13(10):2308.</p>
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3.The Netherlands Diabetes type 2

H2O template country use cases diseases	
Country	The Netherlands
Disease	Diabetes
Objective of the initiative	Diabeter (T1D): Improving diabetes healthcare and minimizing complications of diabetes type 1 in children and young adults. Mi-guide (T2D): Improving the lifestyle of T2D patients
Timeline	To be determined
Collaboration with other hospitals/ nursing homes/ ...?	Diabeter: Deventer, Eindhoven, Groningen, Amsterdam and Rotterdam Mi-guide: start in region Rotterdam
Outcome set(s) used	ICHOM
Which Provider reported data are collected?	Laboratory follow-up data Follow up on complications (micro- and macrovasculair) Medication use
Do data originate from the EPD? Registries? Both?	VCare
Which Patient Reported Outcome Measures (PROMs) used?	WHO-5 PAID (problem areas in Diabetes Questionnaire) PHQ-9 (Patiënt Health Questionnaire) SCQ (Modified Self-Administered Comorbidity Questionnaire) , MY-Q (MIND Youth Questionnaire)
Paper based or digital PROM collection?	Digital

Data dictionary available?	To be filled later
International standard(s) (fe SNOMED CT, LOINC or other international standards)	SNOMED
Common data model used?	
Name of data capture tool, purchased or developed?	Under development
Dashboard for patients available?	Yes
Dashboard for HCP available?	Yes
Name Platform Provider if available	VCare, Mi-guide
Any benchmarking?	Not yet.
Literature references available from research group?	<p>M. de Wit, P. Winterdijk, H.-J. Aanstoot, B. Anderson, T. Danne, L. Deeb, K. Assessing diabetes-related quality of life of youth with type 1 diabetes in routine clinical care: the MIND Youth Questionnaire (MY-Q). <i>Pediatric Diabetes</i>. 2012 Dec; 13 (8): 638-46.</p> <p>Concerning the databank for T2D: E. van't Riet, M.T. Schram, Abbink E.J., Admiraal W.M., M.W. Dijk-Schaap et.al. The diabetes Pearl: diabetes biobanking in the Netherlands. <i>BMJ Public Health</i>. 2021 Nov 6;12:949.</p>

4. The Netherlands IBD

H2O template country use cases diseases	
Example	
Country	The Netherlands
Disease	IBD
Objective of the initiative	<p>IBD Dream: Prospective data collection of PROMs, complications, side effects and disease activity. Making IBD care more transparent and improving the quality of care.</p> <p>IBD Coach: to involve patients with IBD in the management of their own health and improve their communication with HCP. To enable continuous home-monitoring of patients with IBD and optimize disease knowledge.</p>
Timeline	
Collaboration with other hospitals/nursing homes/ ...?	<p>IBD Dream : 5 hospitals in the Netherlands (1 academic hospital) Radboud UMC, Medisch Spectrum Twente, Onze lieve Vrouwe Gasthuis, Franciscus Gasthuis & Vlietland, Rotterdam, Jeroen Bosch Ziekenhuis</p> <p>IBD Coach Started in: Maastricht University Medical Center, Leiden University Medical center, Zuyderland Medical Center, now rapidly expanding (20 hospitals in the Netherlands)</p>
Outcome set(s) used	ICHOM standard set for Inflammatory Bowel disease
Which Provider reported data are collected?	<p>IBD Dream: Use of medications Disease activity</p>

	Side effects Lab results. IBD coach: Morisky medication adherence Scale Side effects Medication usage
Do data originate from the EMR? Registries? Both?	IBDdream and IBD coach EMR as well as an app/website.
Which Patient Reported Outcome Measures (PROMs)	IBDdream: IBD-control questionnaire Work Productivity and activity Impairment questionnaire (WPAI) EuroQol5d IBD coach: Monitor IBD at Home questionnaire (MIAH) Treatment satisfaction Questionnaire for Medication Work productivity (WPAI) EuroQol SF-12 Malnutrition Screening Tool Short inflammatory Bowel disease questionnaire Single questions on fatigue, physical exercise, stress, life-events, anxiety and depression, social support and self-management skills.
Paperbased or digital PROM collection?	IBDdream and IBD coach: Digital (by app and website)
Data dictionary	
International standard(s) (fe SNOMED CT, LOINC or other international standards)	to be filled later
Common data model used?	
Name of data capture tool, purchased or developed?	IBDdream IBD coach: sananet
Dashboard for patients available? Name?	Yes, IBDream and IBDcoach
Dashboard for HCP available?	Yes, IBDream and IBD coach
Name Platform Provider if available	IBD coach: Sananet
Any benchmarking?	Yes, IBDream compares individual HCP and hospitals.
Literature references available from research group?	<u>References on use of IBDream:</u> - M.E. De Jong, E. Taal, P.W.A. Thomas, T.E.H. Romkens, J.M. Jansen, R.L. West, E. Slotman, F. Hoentjen, M.G.V.M. Russel. Cross-cultural translation and validation of the IBD-control questionnaire in the Netherlands: a patient-reported outcome measure in inflammatory bowel disease. <u>References on use of IBD Coach</u> - M.J. De Jong, A.E. van der Meulen-de Jong, M.J. Romberg-Camps, M.C. Becx, J.P. Maljaars, M. Cilissen et. Al. Telemedicine for management of inflammatory bowel disease (my IBDcoach): a pragmatic multicentre, randomized controlled trial.

	<p>Lancet 2017 sep 2; 390 (10098): 959-968</p> <p>-M.J. De Jong, A.E. van der Meulen-de Jong, M.J. Romberg-Camps, M.C. Becx, T. Markus, H. Tomlow et . al. Development and feasibility study of a telemedicine tool for all patients with IBD: MyIBDcoach.</p> <p><u>General references</u></p> <p>-K. Bodger, C. Ormoerd. D. Shackcloth, M. Harrison. Development and validation of a rapid, generic measure of disease control from the patient's perspective: the IBD-control questionnaire. Gut 2013;0:1–11. doi:10.1136/gutjnl-2013-305600</p> <p>-K. Sahnun, P.J. Tozer, S.O. Adegbola. M.J. Lee, N. Heywood, A.G.K. Mcnair, D.Hind et al. Developing a core outcome set for fistulising perianal Crohn's disease. Gut 2019;68:226–238. doi:10.1136/gutjnl-2017-315503</p> <p>-A.H. Kim, C. Roberts, B.G. Feagan, R. Banerjee, W. Bemelman, K. Bodger, M. Derieppe et al. Developing a Standard Set of Patient-centred POutcomes for inflammatory Bowel Disease – an International, Cross-disciplinary Consensus. Journal of Crohn's and Colitis, 2018, 408–418</p> <p>-Cost-effectiveness of Telemedicine-directed Specialized vs Standard Care for Patients With Inflammatory Bowel Diseases in a Randomized Trial https://www.cghjournal.org/article/S1542-3565(20)30535-8/fulltext</p> <p>-</p>
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5. Germany Breast cancer

H2O template country use cases diseases	
Country	Germany
Disease	Metastatic Breast cancer
Objective of the initiative	The aim of the PRO B study is to investigate the effects of an electronic PRO monitoring on fatigue (primary outcome), hospitalisations, and use of rescue services, physical functioning, overall survival in patients with visceral metastasis, overall survival in patients with triple-negative breast cancer, progression-free survival, health-related quality of life, and number of therapy changes (secondary outcomes) among MBC patients in German routine care.
Timeline	2020 - 2023
Collaboration with other hospitals/nursing homes/ ...?	Charité – Universitätsmedizin Berlin (Gynecology, Psychosomatics, Biometrie and clinical epidemiology); Deutsche Krebsgesellschaft e. V., Barmer, BKK and DAK (Health Insurance); OnkoZert GmbH
Outcome set(s) used	Standard set Breast Cancer ICHOM and EORTC Patient Reported outcomes
Which Provider reported data are collected?	/
Do data originate from the EPD? Registries? Both?	IT infrastructure of Deutsche Krebsgesellschaft (DKG) and OnkoZert GmbH
Which Patient Reported Outcome Measures (PROMs) used?	EORTC QLQ-C30 domains using items from the EORTC CAT item banks
Paperbased or digital PROM collection?	Digital (App-based intensified PRO monitoring)
Data dictionary available?	Yes – presented upon request by the research group
International standard(s) (fe SNOMED CT, LOINC or other international standards)	
Common data model used?	yes
Name of data capture tool, purchased or developed?	NeuroSys GmbH
Dashboard for patients available?	yes
Dashboard for HCP available?	yes
Name Platform Provider if available	App and platform are provided by NeuroSys GmbH
Any benchmarking?	Weekly for the intervention group, every 3 months for the control group
Literature references available from research group?	1. Karsten, M.M., Kühn, F., Blohmer, JU. et al. PRO B – „patient-reported outcomes“ bei Brusterkkrankungen. Forum 35, 420–421 (2020). https://doi.org/10.1007/s12312-020-00848-2 2. Karsten MM, Speiser D, Hartmann C, Zeuschner N, Lippold K, Kiver V, Gocke P, Kirchberger V, Blohmer JU. Web-Based Patient-Reported Outcomes Using the

	International Consortium for Health Outcome Measurement Dataset in a Major German University Hospital: Observational Study. JMIR Cancer. 2018 Dec 20;4(2):e11373. doi: 10.2196/11373. PMID: 30573450; PMCID: PMC6320408.
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6. Germany Diabetes type 1

H2O template country use cases diseases	
Country	Germany
Disease	Diabetes (Type 1 and 2)
Objective of the initiative	Development, validation and implementation of Computer-adaptive tests on patient-reported outcomes relevant for diabetes care
Timeline	2021-2023
Collaboration with other hospitals/ nursing homes/ ...?	Charité - Universitätsmedizin Berlin (Endocrinology, Psychosomatics); Deutsche Diabetes Gesellschaft (German Diabetes Society); WinDiab
Outcome set(s) used	Standard set Diabetes ICHOM; a combination of Patient Reported and Provider Reported outcomes
Which Provider reported data are collected?	<ul style="list-style-type: none"> • Diabetes Type • Comorbidities (further information upon request) • Functional health status • (further LAB data)
Do data originate from the EPD? Registries? Both?	Not applicable in Germany
Which Patient Reported Outcome Measures (PROMs) used?	<ul style="list-style-type: none"> • PROMIS-29 including seven HRQoL domains (Physical Functioning, Anxiety, Depression, Fatigue, Sleep Disturbance, Social Functioning, and Pain), and the pain domain has two subdomains (interference and intensity) • Medical Data • Treatment factors (such as type of treatment) • Examination dates • Health behavior (such as smoking, drinking, physical activity) • Socio-demographic data • Disease impact
Paperbased or digital PROM collection?	Paperbased and digital (self-developed tool using RedCap)
Data dictionary available?	no
International standard(s) (fe SNOMED CT, LOINC or other international standards)	/
Common data model used?	yes

Name of data capture tool, purchased or developed?	RedCap
Dashboard for patients available?	Only in Beta-Version
Dashboard for HCP available?	Only in Beta-Version
Name Platform Provider if available	/
Any benchmarking?	Every 6 months
Literature references available from research group?	(ongoing study)

7. Germany IBD

H2O template country use cases diseases	
Country	Germany
Disease	IBD
Objective of the initiative	No projects are known to the research group
Timeline	
Collaboration with other hospitals/ nursing homes/ ...?	
Outcome set(s) used	
Which Provider reported data are collected?	
Do data originate from the EPD? Registries? Both?	
Which Patient Reported Outcome Measures (PROMs) used?	
Paperbased or digital PROM collection?	
Data dictionary available?	
International standard(s) (fe SNOMED CT, LOINC or other international standards)	
Common data model used?	
Name of data capture tool, purchased or developed?	
Dashboard for patients available?	
Dashboard for HCP available?	

Name Provider if available	Platform	
Any benchmarking?		
Literature references available from research group?		

8.Spain Breast cancer

9.Spain Non-small cell Lung cancer

H2O template country use cases diseases		
Country	Spain	
Objective of the initiative		
Timeline		
Collaboration with other hospitals/ nursing homes/ ...?	20 Spanish hospitals	
Outcome set(s) used		
Which Provider reported data are collected?	All the patients' clinical information (including assessment of treatment response) was recorded in the corresponding medical records of the investigator, obtained as part of routine care,	
Do data originate from the EPD? Registries? Both?	EHR (Cf. above)	
Patient Reported Outcome Measures (PROMs) used? Which?	AGPAR 5 constructs (adaptability, partnership, growth, affection, and resolve) validated Spanish version of Duke-UNC-11 scale	
Paper based or digital PROM collection?	Paper?	
Data dictionary available?	NA	
International standard(s) (fe SNOMED CT, LOINC or other international standards)	no	
Name of data capture tool	?	
Dashboard for patients available?	No?	
Dashboard for HCP available?	No?	
Name Provider if available	Platform	
Any benchmarking?		
Literature references available from research group?	https://bmcpyschology.biomedcentral.com/articles/10.1186/s40359-020-00489-z#Sec2 Viñolas N., Garcia-Campelo R., Majem M., Carcereny E., Isla D., Gonzalez-Larriba JL., et al. "Assessment of the psychosocial and economic impact according to sex in non-small	

	cell lung cancer patients: an exploratory longitudinal study” BMC Psychology, 8, Article number: 123 (2020)
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H2O template country use cases diseases	
Country	Spain
Objective of the initiative	
Timeline	
Collaboration with other hospitals/ nursing homes/ ...?	16 other Hospitals and cancer centers
Outcome set(s) used	
Which Provider reported data are collected?	Questionnaire compliance was 77.3% to 99.0% and 68.7% to 99.0% with afatinib and erlotinib, respectively. Significantly more patients who received afatinib versus erlotinib experienced improved scores for GHS/QoL (36% vs. 28%; P = .041) and cough (43% vs. 35%; P = .029). Afatinib significantly delayed TTD in dyspnea (P = .008) versus erlotinib, but not cough (P = .256) or pain (P = .869). Changes in mean scores favored afatinib for cough (P = .0022), dyspnea (P = .0007), pain (P = .0224), GHS/QoL (P = .0320), and all functional scales. Differences in adverse events between afatinib and erlotinib, specifically diarrhea, did not affect GHS/QoL.
Do data originate from the EPD? Registries? Both?	
Patient Reported Outcome Measures (PROMs) used? Which?	EORTC, QoL questionnaire and lung cancer-specific module
Paperbased or digital PROM collection?	Paper
Data dictionary available?	NA
International standard(s) (fe SNOMED CT, LOINC or other international standards)	no
Name of data capture tool	
Dashboard for patients available?	No
Dashboard for HCP available?	No
Name Platform Provider if available	
Any benchmarking?	
Literature references available from research group?	https://www.clinical-lung-cancer.com/article/S1525-7304(17)30175-4/fulltext#secsectitle0050 Felip, E., et al “Symptom and Quality of Life Improvement in LUX-Lung 8, an Open-Label Phase III Study of Second-Line Afatinib Versus Erlotinib in Patients With Advanced Squamous Cell Carcinoma of the Lung After First-Line Platinum-Based Chemotherapy” <i>clinical Lung Cancer</i> , 19(1): 74-83 (2018) https://pubmed.ncbi.nlm.nih.gov/28729180/

H2O template country use cases diseases	
Country	Spain
Objective of the initiative	

Timeline	
Collaboration with other hospitals/ nursing homes/ ...?	Collaboration with other 19 different institutions from different 7 countries
Outcome set(s) used	EORTC, QLQ-C30, QLQ-LC13
Which Provider reported data are collected?	
Do data originate from the EPD? Registries? Both?	
Patient Reported Outcome Measures (PROMs) used? Which?	PRO measures, including global quality of life (QoL), functioning domains and symptoms, were assessed by the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQ-C30) and the 13-item Lung Cancer (QLQ-LC13) module.
Paper based or digital PROM collection?	Paper
Data dictionary available?	NA
International standard(s) (fe SNOMED CT, LOINC or other international standards)	no
Name of data capture tool	
Dashboard for patients available?	No
Dashboard for HCP available?	No
Name Platform Provider if available	255 patients completed baseline and ≥ 1 post-baseline PRO assessment. Most patients had CM improvement (42.4 %) or stable (38.0 %) scores for global QoL. Functioning domains with the greatest proportion of patients with improved scores were role (37.6 %) and emotional (36.9 %); only one domain had more patients showing worsening than improving function (cognitive [24.3 % vs 22.4 %]). Most patients showed improved or stable scores for disease-related symptoms. No QLQ-C30 symptom domains had more patients worsening than improving. Symptoms on the QLQ-C30 scale with the greatest proportion of patients with improved scores were fatigue (49.4 %) and insomnia (46.3 %). Four QLQ-LC13 domains had more patients worsening than improving (two most affected were peripheral neuropathy [37.3 % vs 13.7 %] and alopecia [19.2 % vs 13.3 %]). Symptoms on the QLQ-LC13 scale with the greatest proportion of patients with improved scores were cough (42.7 %) and pain in other parts (32.9 %).
Any benchmarking?	
Literature references available from	https://pubmed.ncbi.nlm.nih.gov/32344248/ https://www.lungcancerjournal.info/article/S0169-5002(20)30308-1/fulltext

research group?	Peters S., T Shaw, A., Besse, B., Felip E., et al “Impact of lorlatinib on patient-reported outcomes in patients with advanced ALK-positive or ROS1-positive non-small cell lung cancer” <i>Lung Cancer</i> , 144:10-19 (2020) https://pubmed.ncbi.nlm.nih.gov/32344248/
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H2O template country use cases diseases	
Country	Spain
Objective of the initiative	
Timeline	
Collaboration with other hospitals/nursing homes/...?	Collaboration with other 14 different institutions from different 7 countries
Outcome set(s) used	EORTC, QLQ-C30, QLQ-LC13
Which Provider reported data are collected?	All 140 patients enrolled had received two or more previous treatment regimens, and all patients had received crizotinib. The median duration of exposure and the follow-up time with ceritinib were 8.8 months (range, 0.1 to 19.4 months) and 11.3 months (range, 0.1 to 18.9 months), respectively. Investigator assessed overall response rate was 38.6% (95% CI, 30.5% to 47.2%). Secondary end points, all investigator assessed, included disease control rate (77.1%; 95% CI, 69.3% to 83.8%), time to response (median, 1.8 months; range, 1.6 to 5.6 months), duration of response (median, 9.7 months; 95% CI, 7.1 to 11.1 months), and progression-free survival (median, 5.7 months; 95% CI, 5.4 to 7.6 months). Of 100 patients with baseline brain metastases, 20 had active target lesions at baseline; investigator-assessed intracranial overall response rate was 45.0% (95% CI, 23.1% to 68.5%). The most common adverse events (majority, grade 1 or 2) for all treated patients were nausea (81.4%), diarrhea (80.0%), and vomiting (62.9%). Patient-reported outcomes showed a trend toward improved symptom burden.
Do data originate from the EPD? Registries? Both?	
Patient Reported Outcome Measures (PROMs) used? Which?	PROs were evaluated with the Lung Cancer Symptom Scale and European Organisation for Research and Treatment of Cancer surveys (the core-30 and the 13-item lung cancer-specific quality-of-life questionnaires)
Paper based or digital PROM collection?	Paper
Data dictionary available?	NA
International standard(s) (fe SNOMED CT, LOINC or other international standards)	no
Name of data capture tool	
Dashboard for patients	No

available?	
Dashboard for HCP available?	No
Name Platform Provider if available	
Any benchmarking?	
Literature references available from research group?	Crinò L., Ahn M.-J., De Marinis F., (...) Felip E., et al. "Multicenter phase II study of whole-body and intracranial activity with ceritinib in patients with ALK-rearranged non-small-cell lung cancer previously treated with chemotherapy and crizotinib: Results from ASCEND-2" <i>Journal of Clinical Oncology</i> , vol. 34, issue 24, p. 2866 – 2873 (2016). https://pubmed.ncbi.nlm.nih.gov/27432917/

H2O template country use cases diseases	
Country	Spain
Objective of the initiative	
Timeline	
Collaboration with other hospitals/ nursing homes/ ...?	Collaboration with other 17 different institutions from different 7 countries
Outcome set(s) used	EORTC, QLQ-C30, QLQ-LC13
Which Provider reported data are collected?	Between Feb 26, 2016, and March 6, 2017, 616 patients were enrolled; median follow-up was 10.5 months (range 0.2–20.4) as of data cutoff on Nov 8, 2017. 402 (99%) of 405 patients in the pembrolizumab plus pemetrexed–platinum group and 200 (99%) of 202 patients in the placebo plus pemetrexed–platinum-treated group completed at least one PRO assessment. At baseline, 359 (89%) of 402 patients in the pembrolizumab plus pemetrexed–platinum group and 180 (90%) of 200 in the placebo plus pemetrexed–platinum group were compliant with QLQ-C30; at week 12, 319 (90%) of 354 and 149 (89%) of 167 patients were compliant, respectively; and at week 21, 249 (76%) of 326 and 91 (64%) of 143 patients were compliant, respectively. From baseline to week 12, GHS/QOL scores were maintained with both pembrolizumab plus pemetrexed–platinum (least-squares mean change: 1.0 point [95% CI –1.3 to 3.2] increase) and placebo plus pemetrexed–platinum (–2.6 points [–5.8 to 0.5] decrease; between-group difference: 3.6 points [–0.1 to 7.2]; p=0.053). From baseline to week 21, GHS/QOL scores were better maintained with pembrolizumab plus pemetrexed–platinum (least-squares mean change: 1.3 points [95% CI –1.2 to 3.6] increase) than with placebo plus pemetrexed–platinum (–4.0 points [–7.7 to –0.3] decrease; between-group difference: 5.3 points [1.1 to 9.5]; p=0.014). Median time to deterioration in cough, chest pain, or dyspnoea was not reached (95% CI 10.2 months to not reached) with pembrolizumab plus pemetrexed–platinum, and was 7.0 months (4.8 months to not reached) with placebo plus pemetrexed–platinum (hazard ratio 0.81 [95% CI 0.60–1.09], p=0.16). Interpretation: The addition of pembrolizumab to standard chemotherapy maintained GHS/QOL, with improved GHS/QOL scores at week 21 in the pembrolizumab plus chemotherapy group compared with the placebo plus chemotherapy group. These data further support use of pembrolizumab plus pemetrexed–platinum as first-line therapy for patients with metastatic non-squamous non-small-cell lung cancer.
Do data originate from the EPD? Registries?	

Both?	
Patient Reported Outcome Measures (PROMs) used? Which?	PROs were evaluated with the Lung Cancer Symptom Scale and European Organisation for Research and Treatment of Cancer surveys (the core-30 and the 13-item lung cancer-specific quality-of-life questionnaires)
Paper based or digital PROM collection?	Paper
Data dictionary available?	NA
International standard(s) (fe SNOMED CT, LOINC or other international standards)	no
Name of data capture tool	
Dashboard for patients available?	No
Dashboard for HCP available?	No
Name Platform Provider if available	
Any benchmarking?	
Literature references available from research group?	Grassino M. C., Gadgeel S., Esteban E., Filip E., et al "Patient-reported outcomes following pembrolizumab or placebo plus pemetrexed and platinum in patients with previously untreated, metastatic, non-squamous non-small-cell lung cancer (KEYNOTE-189): a multicentre, double-blind, randomised, placebo-controlled, phase 3 trial" <i>The Lancet Oncology</i> vol. 21, issue 3, p. 3870-0397 (2020) https://pubmed.ncbi.nlm.nih.gov/32035514/

H2O template country use cases diseases	
Country	Spain
Disease	Non-small cell Lung cancer
Collaboration with other hospitals/ nursing homes/ ...?	
Outcome set(s) used	APGAR, relationship impact scale, DUKE-UNC scale, economic impact in patients and caregiver, and Zarit scale.
Which Provider reported data are collected?	333 patients were included. Most families reported to continue being functional despite the lung cancer diagnosis. Regardless of sex, they did not perceive changes in their partner relationship. Most patients felt their social support was normal. Roughly 25% of people reported a worsening in their economic situation, without remarkable differences by sex. Statistically significant differences were found between both groups regarding the caregiver's relationship to the patient (more parents were the caregiver in females than in males, $p < 0.0001$) and the caregiver's employment situation (more employed caregivers in females) ($p < 0.0001$). Most caregivers of both sexes considered that taking care of their relative did not pose a significant burden.
Do data originate from the EPD? Registries?	

Both?	
Patient Outcome (PROMs) Which?	Reported Measures used?

10. Spain Diabetes Type 1 and 2

H2O template country use cases diseases	
Country	Spain
Objective of the initiative	
Timeline	
Objective of the initiative	Development, validation and implementation of Computer-adaptive tests on patient-reported outcomes relevant for diabetes care
Timeline	2021-2023
Collaboration with other hospitals/ nursing homes/ ...?	Hospital Vall d'Hebron, Barcelona (HVH). Catalan Health Institut- Institut Català de la Salut (ICS)
Outcome set(s) used	Provider Reported outcomes
Which Provider reported data are collected?	<ul style="list-style-type: none"> • Diabetes Type • Comorbidities (further information upon request) • Functional health status • (further LAB data)
Do data originate from the EPD? Registries? Both?	Registries
Which Patient Reported Outcome Measures (PROMs) used?	<ul style="list-style-type: none"> • Medical Data • Treatment factors (such as type of treatment) • Examination dates • Health behavior (such as smoking, drinking, physical activity) • Socio-demographic data
Paperbased or digital PROM collection?	Paperbased and digital (collected by provider upon interrogatory or paperbased questionnaires)
Data dictionary available?	no
International standard(s) (fe SNOMED CT, LOINC or other international standards)	/
Common data model used?	yes
Name of data capture tool, purchased or developed?	e-CAP, developed by ICS

Dashboard for patients available?	NO
Dashboard for HCP available?	Yes
Name Platform Provider if available	La Meva Salut/ Generalitat de Catalunya (Regional Catalanian Government)
Any benchmarking?	Undetermined
Literature references available from researchgroup?	(ongoing study)

11. Spain IBD

H2O template country use cases diseases	
Country	Spain
Objective of the initiative	
Timeline	
Collaboration with other hospitals/ nursing homes/ ...?	No
Outcome set(s) used	Harvey-Bradshaw index (HBI) ¹ , simple clinical colitis activity index (SCCAI) ² ¹ Harvey RF, Bradshaw JM. A simple index of Crohn's-disease activity. Lancet. 1980 Mar 8;1(8167):514. PubMed PMID: 6102236. ² Walmsley RS, Ayres RC, Pounder RE, Allan RN. A simple clinical colitis activity index. Gut. 1998 Jul;43(1):29-32. PubMed PMID: 9771402. Pubmed Central PMCID: 1727189.
Which Provider reported data are collected?	---
Do data originate from the EPD/ EMR? Registries? Both?	Electronic medical records
Patient Reported Outcome Measures (PROMs) used? Which?	Yes, Inflammatory Bowel Disease Questionnaire – 36 items (IBDQ36) Lopez-Vivancos J, Casellas F, Badia X, Vilaseca J, Malagelada JR. Validation of the spanish version of the inflammatory bowel disease questionnaire on ulcerative colitis and Crohn's disease. Digestion. 1999;60(3):274-80. PubMed PMID: 10343142.
Paperbased or digital PROM collection?	Paper based
Data dictionary	No
International standard(s) (fe SNOMED CT, LOINC or other international standards)	No
Name of data capture tool	None
Dashboard for patients available?	No
Dashboard for HCP available?	No

Name	Platform	Systems, Applications, Products in Data Processing (SAP)
Provider if available		
Any benchmarking?		Annual internal audit and once every three years, external audit with formal accreditation.
Literature references available from researchgroup?		<p><u>References on use of PROMs in IBD of the HUVH-UACC group:</u></p> <ul style="list-style-type: none"> - Rapidity of clinical response to adalimumab and improvement of quality of life in luminal Crohn's disease: RAPIDA study. Marín-Jiménez I, Acosta MB, Esteve M, Castro-Laria L, García-López S, Ceballos D, Echarri A, Martín-Arranz MD, Busquets D, Llaó J, Navarro-Llavat M, Huguet JM, Argüelles-Arias F, Vicente R, Boudet JM, Díaz G, Sánchez-Migallón AM, Casellas F; for RAPIDA trial investigators. Gastroenterol Hepatol. 2021 May 27;S0210-5705(21)00168-0. doi: 10.1016/j.gastrohep.2021.04.010. - Normalization of long-term quality of life in Crohn's disease patients receiving ustekinumab. Marquès-Camí M, Robles Alonso V, Borrueal N, Herrera de Guise C, Mayorga L, Casellas F. Rev Esp Enferm Dig. 2021 May;113(5):313-317. doi: 10.17235/reed.2020.6941/2020. - van Egdom LSE, Hazelzet JA, Koppert LB. 'Reply to: Moving forward with value-based healthcare: The need for a scientific approach. Eur J Surg Oncol. 2019 Jul;45(7):1300. - A Global, Prospective, Observational Study Measuring Disease Burden and Suffering in Patients with Ulcerative Colitis Using the Pictorial Representation of Illness and Self-Measure Tool. Ghosh S, Sensky T, Casellas F, Rioux LC, Ahmad T, Márquez JR, Vanasek T, Gubonina I, Sezgin O, Ardizzone S, Kligys K, Petersson J, Suzuki Y, Peyrin-Biroulet L. J Crohns Colitis. 2020 Jul 29;15(2):228-37. doi: 10.1093/ecco-jcc/jjaa159. Online ahead of print. PMID: 32722760 - A Qualitative Research for Defining Meaningful Attributes for the Treatment of Inflammatory Bowel Disease from the Patient Perspective. Louis E, Ramos-Goñi JM, Cuervo J, Kopylov U, Barreiro-de Acosta M, McCartney S, Rosenfeld G, Bettenworth D, Hart A, Novak K, Donnet X, Easton D, Saldaña R, Protze K, Tzur E, Alperovich G, Casellas F. Patient. 2020 Jun;13(3):317-325. doi: 10.1007/s40271-019-00407-5. PMID: 31997116 - Patient preferences for inflammatory bowel disease treatment objectives. Casellas F, Herrera-de Guise C, Robles V, Navarro E, Borrueal N. Dig Liver Dis. 2017 Feb;49(2):152-156. doi: 10.1016/j.dld.2016.09.009. Epub 2016 Sep 21. PMID: 27717791 - Iron Deficiency in the Absence of Anemia Impairs the Perception of Health-Related Quality of Life of Patients with Inflammatory Bowel Disease. Herrera-deGuise C, Casellas F, Robles V, Navarro E, Borrueal N. Inflamm Bowel Dis. 2016 Jun;22(6):1450-5. doi: 10.1097/MIB.0000000000000768. PMID: 27057682 - Predictive value of early restoration of quality of life in Crohn's disease patients receiving antitumor necrosis factor agents. Herrera-deGuise C, Casellas F, Robles V, Navarro E, Borrueal N. J Gastroenterol Hepatol. 2015 Feb;30(2):286-91. doi: 10.1111/jgh.12803. PMID: 25302652 - Patients' perceptions, attitudes, and experiences about the management of mild-to-moderate ulcerative colitis. Casellas F, Vicens DG, Menéndez SR, Oliver NA. J Crohns Colitis. 2014 Sep;8(9):1097-107. doi: 10.1016/j.crohns.2014.02.013. Epub 2014 Mar 5. PMID: 24613279 - Questionnaires for measuring fatigue and its impact on health perception in inflammatory bowel disease. Castillo-Cejas MD, Robles V, Borrueal N, Torrejón A, Navarro E, Peláez A, Casellas F. Rev Esp Enferm Dig. 2013 Mar;105(3):144-53. doi: 10.4321/s1130-01082013000300005. PMID: 23735021 - Mucosal healing restores normal health and quality of life in patients with inflammatory bowel disease. Casellas F, Barreiro de Acosta M, Iglesias M, Robles V, Nos P, Aguas M, Riestra S, de Francisco R, Papo M, Borrueal N. Eur J Gastroenterol Hepatol. 2012 Jul;24(7):762-9. doi: 10.1097/MEG.0b013e32835414b2. PMID: 22517240 - Restoration of quality of life of patients with inflammatory bowel disease after one year

	<p>with antiTNFalpha treatment. Casellas F, Robles V, Borrueal N, Torrejón A, Castells I, Navarro E, Guarner F. J Crohns Colitis. 2012 Oct;6(9):881-6. doi: 10.1016/j.crohns.2012.01.019. Epub 2012 Feb 14. PMID: 22398074</p> <p>- Cutoff values of the Inflammatory Bowel Disease Questionnaire to predict a normal health related quality of life. Huamán JW, Casellas F, Borrueal N, Peláez A, Torrejón A, Castells I, Masachs M, Varela E, Guarner F. J Crohns Colitis. 2010 Dec;4(6):637-41. doi: 10.1016/j.crohns.2010.07.006. Epub 2010 Aug 2. PMID: 21122573</p> <p>- Factors that impact health-related quality of life in adults with celiac disease: a multicenter study. Casellas F, Rodrigo L, Vivancos JL, Riestra S, Pantiga C, Baudet JS, Junquera F, Diví VP, Abadia C, Papo M, Gelabert J, Malagelada JR. World J Gastroenterol. 2008 Jan 7;14(1):46-52. doi: 10.3748/wjg.14.46. PMID: 18176960</p> <p>- Spanish translation, adaptation, and validation of the 32-item questionnaire on quality of life for inflammatory bowel disease(IBDQ-32)]. Masachs M, Casellas F, Malagelada JR. Rev Esp Enferm Dig. 2007 Sep;99(9):511-9. doi: 10.4321/s1130-01082007000900006. PMID: 18052646</p>
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12. Austria Breast cancer

H2O template country use cases diseases	
Country	Austria
Objective of the initiative	
Timeline	
Objective of the initiative	<p>The aim of this initiative is to integrate e-PROMs in the routine health care process including linking them to the clinical data at the breast cancer outpatient clinic in the general hospital of Vienna.</p> <p>The e- PROMS will be available in German, English and Turkish (the languages identified as most needed according to the majority of patients visiting the hospital) to ensure maximum inclusion for all patients.</p>
Timeline	2021 - 2025
Collaboration with other hospitals/ nursing homes/ ...?	A collaboration between the Medical University of Vienna and the Vienna general Hospital
Outcome set(s) used	The standardized ICHOM Breast Cancer PROMs set and the the Body Image Scale
Which Provider reported data are collected?	Please see ICHOM publication regarding recommendations of Breast Cancer set of PROMs: https://ichom.org/files/medical-conditions/breast-cancer/breast-cancer-reference-guide.pdf
Do data originate from the EPD? Registries? Both?	The Research, Documentation and Analysis system (RDA) which is designed to capture the PROMs digitally will be linked to the existing patient profile in the EMR (AKIM - Allgemeines Krankenhaus Informations Management database system at the general hospital of Vienna)
Which Patient Reported Outcome Measures (PROMs) used?	<ol style="list-style-type: none"> 1.The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) 2.The European Organization for Research and Treatment of Cancer Breast Cancer-Specific Quality of Life Questionnaire (EORTC QLQ-BR23)

	<p>3. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-LMC21)</p> <p>4. The Functional Assessment of Cancer Therapy Endocrine Subscale (FACT-ES)</p> <p>5. The BREAST-Q Patient Reported Outcomes Instrument (BREAST-Q)</p> <p>6. The Body Image Scale (BIS)</p>
Paperbased or digital PROM collection?	Mainly Digital, however, paper-based could also be used whenever needed.
Data dictionary available?	No
International standard(s) (fe SNOMED CT, LOINC or other international standards)	
Common data model used?	A standardized set is used
Name of data capture tool, purchased or developed?	The patient will receive a link on the personal electronic devices which will direct the patient to an online questionnaire comprising the included e-PROMs.
Dashboard for patients available?	Not yet implemented
Dashboard for HCP available?	Not yet implemented
Name Platform Provider if available	Provided by the Research, Documentation and Analysis system (RDA) at the medical university of Vienna.
Any benchmarking?	Not internally but in the context of the European University Hospital Alliance (EUHA)
Literature references available from researchgroup?	<ol style="list-style-type: none"> 1. Cossio-Gil, Y., Stamm, T., Omara, M., Watson, C., Casey, J., Chakhunashvili, A., ... & Hazelzet, J. (2021). The roadmap for implementing value-based healthcare in European university hospitals-consensus report and recommendations. medRxiv (under revision) 2. Stamm, T.A. et al., 2011. Concepts of functioning and health important to people with systemic sclerosis: a qualitative study in four European countries. Annals of the Rheumatic Diseases, 70(6), pp.1074–1079. 3. Omara, M. et al., 2019. Rasch model of the Child Perceptions Questionnaire for oral health-related quality of life. The Journal of the American Dental Association.

13. Austria Diabetes type 1 + 2

H2O template country use cases diseases	
Country	Austria
Disease	Diabetes (Type 1 and 2)
Objective of the initiative	Use of MySugr App in Austria (driven by Roche Austria)

Timeline	Ongoing
Collaboration with other hospitals/ nursing homes/ ...?	Primary care, but also in clinics
Outcome set(s) used	Outcomes set from MySugr
Which Provider reported data are collected?	<ul style="list-style-type: none"> • Sociodemographic data (personal data optional) • Diabetes type • Type of pump and measurement device, type of smart phone • Blood glucose – automated data transfer from device to App • Infos on calories of food, etc. • Emotional context in a specific situation • PROMs, e.g. stress, collected by patients
Do data originate from the EPD? Registries? Both?	Registries
Which Patient Reported Outcome Measures (PROMs) used?	<ul style="list-style-type: none"> • Medical Data • Treatment factors (such as type of treatment) • Examination dates • Health behavior (such as smoking, drinking, physical activity) • Socio-demographic data
Paperbased or digital PROM collection?	Digital
Data dictionary available?	To be clarified
International standard(s) (fe SNOMED CT, LOINC or other international standards)	To be clarified
Common data model used?	Not yet implemented
Name of data capture tool, purchased or developed?	MySugr App, via Roche diabetes care platform (cloud-based service) data can be shared with providers
Dashboard for patients available?	Yes
Dashboard for HCP available?	Yes
Name Platform Provider if available	MySugr App, via Roche diabetes care platform
Any benchmarking?	Currently not done; data only available on a country level
Literature references available from researchgroup?	Ongoing

14. Austria IBD/Austria Lung Cancer

Under development