

Patients' online record access – opportunities & challenges: Germany

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9th November 2022, Uppsala



Legal and political preconditions

- Constitutional law: The right to informational self-determination
 - defines the right to informational self-determination based the general right of personality
- Patients' Rights Act of German Civil Code
 - right to access the original patient file
 - legal representatives – appointed for the area of health care
- (Model) of Professional Code for physicians practising in Germany (MBO)
 - Doctors shall, at the request of patients, grant them access to documentation concerning them, unless there are substantial therapeutic reasons or substantial rights of the patient upon their request, unless there are substantial therapeutic reasons or substantial rights of the doctor or third or the rights of third parties" (Section 10, paragraph 2 MBO).

Practical access to patient records

Practical impact:

- access to files dependent on patient efforts (debt to be discharged) - association of mistrust
- long way to get paper copies
- hardly known, rarely used
- digital change can support voluntary obligation to bring

New steps:

- ePA – the electronic patient record
- offer of (each) statutory health insurance (01/2021)
- medical practice / clinic software - interface to ePA telematics infrastructure

ePA - the electronic patient record

Goal:

- all treatment information is centrally available instead of individual (paper) folders
- no time needed to gather information
- avoid duplicate medical screening or examinations

What to find?

- physician's letter, emergency data, findings from examinations, blood values, medication plans entered by medical staff
- from 2022 on Vaccination certificate, dental bonus booklet, maternity passport
- notes / routine entries by caregivers not included

Who handles access?

- patient decides what is saved or deleted
- patient manages release – what, who, when (doctors, therapists, pharmacists)
- app for smartphone or tablet, desktop PC planned

→ still different to open notes

Barriers for patients' online record access

- Lack of basic understanding - data protection concerns
 - perception that data is generated online through OpenNotes Data insecure
 - unaware that OpenNotes are based on real contacts / conversations
 - more attitude than product or software
 - cultural gap - patient portals
- Concerns of clinicians
 - -similar to other countries
 - concern about being able to view sensitive health data online
 - relationship of trust between doctor and patient
 - misunderstandings, technical terms difficult to understand
 - more time required for discussion about notes and documentation

References:

<https://blogs.bmj.com/bmj/2021/04/01/tobias-esch-integrating-opennotes-and-promoting-self-management-in-primary-care-in-germany-the-witten-model/>
Bertelsmann Stiftung (Hrsg.) 2020: Akteneinsicht Chancen und Umsetzung von OpenNotes in Deutschland. DOI 10.11586/2020045

Barriers for patients' online record access

- Technical requirements, interfaces
 - separate clinic systems, no uniform administration
 - digitisation of patient records
 - protection against unauthorised access
- Use of ePA
 - individual health insurance fund provides ePA
 - patient controls record keeping - possibly incomplete
 - information of a consultation possibly distributed over several subjects, coordination
- Lack of willingness to finance and implement
 - stakeholders focus on costs
 - comprehensive funding is pending

Chances for patients' online record access

- experience in other countries
 - concerns can mostly be overcome
- discussion about possible applications and consequences started
- pilot projects started
 - positive feedback from patients and clinicians
 - particular field of psychiatric care showed openness to the idea
- extended implementation conceivable
 - collaborative notes
 - audio files or short films at the end of the consultation
 - Doctor's letters in patient-oriented language - What do I have?
- digitalisation planned and started small scale (e-prescription)

Pilot Project - The Witten model

- University's Primary Health Care Service at University of Witten/Herdecke (Tobias Esch)
 - making all notes voluntarily available to patients (medical reports and notes of consultations)
 - started 2019, March 2020 about 1000 patients signed up

Accompanying evaluation:

- repeated questionnaires every three months
- almost all patients welcomed opportunity and closer interaction
- clinicians valued describing more carefully and flattening hierarchy
- worries about medical liability issues, legal implications
- technical challenges – patient portal to be improved

Witten Modell example

Patient Date of birth Krankenkasse

Date	Type	ICD-10	Code	Description	Status	User	physician

Patient: Geburtstag:
 Kasse: TK (Nr:)



Datum	Type	Katalog	Code	Beschreibung	Fall	Status	Nutzer	Arzt
10.09.2020	Extern			Patientenfragebogen Corona PDF	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
03.09.2020	Kommunikation			Pat. holt seine Überweisung ab	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
03.09.2020	Überweisung			Dermatologie PDF	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
03.09.2020	Diagnose	ICD-10	I83.1 V	Varizen der unteren Extremitäten mit Entzündung	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
03.09.2020	Anamnese			Email an Pat. geschickt, mitgeteilt, dass er sich in der Dema <input type="text"/> vorstellen möge, bzgl abschließender Diagnose bei Fetechien an den Beinen	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
03.09.2020	Kommunikation			Befund sda gefaxt an: <input type="text"/>	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
27.08.2020	Kommunikation			Rezept wurde von Frau abgeholt	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
27.08.2020	Anamnese			Telefonat Besprechung des Kardiologen Berichtes. Demzufolge Metoprolol starten und Statin weiter, Pat verträgt es gut, WV am 10.09. zur BE	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
27.08.2020	Kassenrezept			Kassenrezept (16), (1) Rosuvastatin Aristo 10 mg 100 Filmtabletten N3 0-0-1 (2) Metoprolol Succinat TAD9-95 mg 100 Retardtbl. N3 0-5-0-5 PDF	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
27.08.2020	Medikament	MMI	11562445 V	Metoprolol Succinat TAD9-95 mg 100 Retardtbl. N3	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
27.08.2020	Medikament	MMI	12598609 V	Rosuvastatin Aristo 10 mg 100 Filmtabletten N3	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
10.08.2020	Extern			Kardiologie Bericht vom 06.08.20 PDF	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
21.07.2020	Extern			Befund, Gefäßpraxis Kerppehelle vom 13.07.2020 Status idem C8M PDF	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
09.07.2020	Anamnese			Verlaufsbesprechung des Labor, war beim Urologen, PBA 1,64, keine Auffälligkeiten, Oberbauchsono unauffällig, WV bei Bedarf, spätestens im Oktober.	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
09.07.2020	Kassenrezept			Kassenrezept (16), PDF	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Labordaten			Universitätsambulanz Witten / Herdecke, [T] Teilbefund (...) JFPC7ON 0.07ng/mlNA 143mmol/L 4.7mmol/lPHOS 3.2mg/dlCA 2.55mmol/lOPT 33URGOT 39URGOT 41UMKREA 1mg/dlFRCHD 95mmol/l7.3mg/dlOFHS 5.2mg/dlCRPST 1.5mg/dlCHOL 278mg/dlLDL 174mg/dlHDL 95mg/dlTRIG 114mg/dlHCYSTE HBA1IF <input type="text"/>	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Laborerschein			Labor-Auftrag <input type="text"/>	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Laborerschein			Labor-Auftrag <input type="text"/> (EDTA-Blut/Parathormon, intakd (PTH) (EPK) (L)-homocystein (LC-MS)G amms-OT [GOT]Phosphat, anorganisch (PHOS)Harnsäure (HS)Vitamin D 25 (25-Hydroxy-Cholecalciferol)Natrium (SE) Phosphat, anorganisch (PHOS) <input type="text"/>	OKV	Validiert	Christina.Baumann-Neuert	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Formular			Patientenfragebogen Corona-Virus JPO	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Leistung	EDM	99037	I48 Faltpauschale	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Diagnose	ICD-10	I48.0	I48 Faltpauschale	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Diagnose	ICD-10	I48.0 B	Chronischer supraventrikulärer Tachykardie	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Diagnose	ICD-10	I48.0 + B	Chronischer supraventrikulärer Tachykardie	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Diagnose	ICD-10	I80.2B ZL	Thrombose, Phlebitis und Thrombophlebitis sonstiger tiefer Gefäße der unteren Extremitäten	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Diagnose	ICD-10	I83.9 0 B	Varizen der unteren Extremitäten ohne Ulzeration oder Entzündung	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.
06.07.2020	Diagnose	ICD-10	I87.20 G L	Venöse Insuffizienz (chronisch) (peripher) ohne Ulzeration	OKV	Validiert	anna.kohnke	Dr. med. Burkhard Heuß, Dermatol.

Reference: Universitätsambulanz für Integrative Gesundheitsversorgung und Naturheilkunde an der Universität Witten / Herdecke Bertelsmann Stiftung (Hrsg.) 2020: Akteneinsicht Chancen und Umsetzung von OpenNotes in Deutschland. DOI 10.11586/2020045

Pilot Projekt Brandenburg Medical School Theodor Fontane

- PEPPSY- Piloting and evaluation of a participatory patient file in psychiatry and somatics
 - started in 2021 in a psychiatric day-care hospital
 - exploration of expectations, opinions, effects and implementation issues
 - expansion prepared for other clinical specialty

Accompanying evaluation:


- Mixed-method design, pre-post comparison
- participatory
- questionnaires, observation, semi-structured interviews
- patientes welcomed opportunity, concerns of clinicians


MHB example


The screenshot shows a web interface for a patient note. At the top left, it says 'PEPPSY Patients'. In the center, there is a 'Bild-in-Bild' icon. On the top right, there is a user profile for 'Mario Rossi', a notification bell, and a language selector set to 'EN' with a US flag. The main content area has a title 'Session 5 - I notice improvements!' and a patient name 'Lucas Skywalker'. Below the title, it says 'Therapist, Mario Rossi' and the date 'May 2, 2022 11:43 AM'. The note text reads: 'Hi! This session was much better than the last one. Please let me know how the meditation is going and if you have any questions.' To the right of the text are two buttons: 'Edit note' and 'Delete entry'. Below the note is a 'Comments' section. A comment from 'Patient, Lucas Skywalker' dated 'May 2, 2022 11:44 AM' says: 'Hi! Thank you for the session. I want to try guided meditation, do you have any recommendations?'. Below the comment is a text input field with the text 'I recommend the ap' and a 'Save' button.


Entries


No filter ▾


-  [Session 4 - You're going good!](#) Doctors, 5/2/2022

Hi Lucas! This was a great lesson, I am seeing a lot of progress and I would suggest you start with mindfulness to counteract the...
-  [Session 3](#) Nurses, 4/26/2022

This was a good lesson
-  [Some notes about Lucas](#) Nurses, 4/25/2022

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis...
-  [Session 2](#) Nurses, 4/25/2022

Great job!
-  [Another entry](#) Nurses, 4/23/2022

Consectetur. Suspendisse ligula dolor, varius nec, vulputate id, luctus sed, lacus. Pellentesque purus urna, porta molestie, mattis non, posuere et, velit. Curabitur diam mauris, dictum...
-  [I did this again](#) Nurses, 4/23/2022

Consectetur. Suspendisse ligula dolor, varius nec, vulputate id, luctus sed, lacus. Pellentesque purus urna, porta molestie, mattis non, posuere et, velit. Curabitur diam mauris, dictum...

Projekt „TelPa_kids“

- Telemedicine in specialised outpatient palliative care for children, adolescents and young adults in Hesse
 - duration 2022-2023
 - development of an App for Smartphones and Tablet PCs
 - data protection compliant communication
 - rapid personal contact in acute crisis (respiratory distress, seizures)
 - supports nursing and medical orders - "please take now medication xy".
 - complement to home visits - not a substitute
 - diagnostics (electric stethoscope for breathing sounds)
 - ask questions, ask for appointments

<https://www.kleine-riesen-nordhessen.de/>



Conclusion

- promising approaches
- positive feedback from patients and clinicians
- more pilot projects needed
- helpful experience from other countries
- publicity - stakeholder education
- create technical conditions

Thank you.

Videodemonstration:

<https://youtu.be/BF91uPDQ2Nc> [youtu.be]

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