

Addressing unmet patient needs

THE PATIENT PERSPECTIVE

*Christine Dehn, German Heart Foundation,
The EU funding landscape: promoting innovation for
cardiovascular health, 28 June 2021*



Introduction

- German Heart Foundation
 - Largest patient organisation for CVD in Germany
 - > 100,000 individual members
 - Main tasks: patient education, prevention + funding research

Find out more:

[doi:10.1093/eurheartj/ehy428](https://doi.org/10.1093/eurheartj/ehy428)

■ European Heart Network

- The European Heart Network (EHN) is a Brussels-based alliance of foundations and associations dedicated to fighting heart disease and stroke and representing patients throughout Europe
- 28 member organisations in 25 countries in Europe
- EHN members' outreach is over 2 million patients and carers

Setting the scene

- Healthcare in Germany/EU
- Political Awareness
- Role of clinical studies
- Real needs
- Patient organisations' role

Germany – the ideal country?

- World's fourth largest market for pharmaceuticals
- Largest market in Europe
- Germany ranks fourth in the world as location for conducting clinical trials

Reimbursement in Germany

Once a pharmaceutical product is available **on the market**, it is immediately eligible for **reimbursement** from the SHI funds.

German Health Care System

- ~ 80 million inhabitants
 - ~ 71 million covered by statutory health insurance (SHI)
 - ~ 9 million covered by private health insurance (PHI)
- > Health insurance is **mandatory** for German citizens

Inequalities in access to healthcare

Deutsche
Herzstiftung



The European Pillar of Social Rights states that

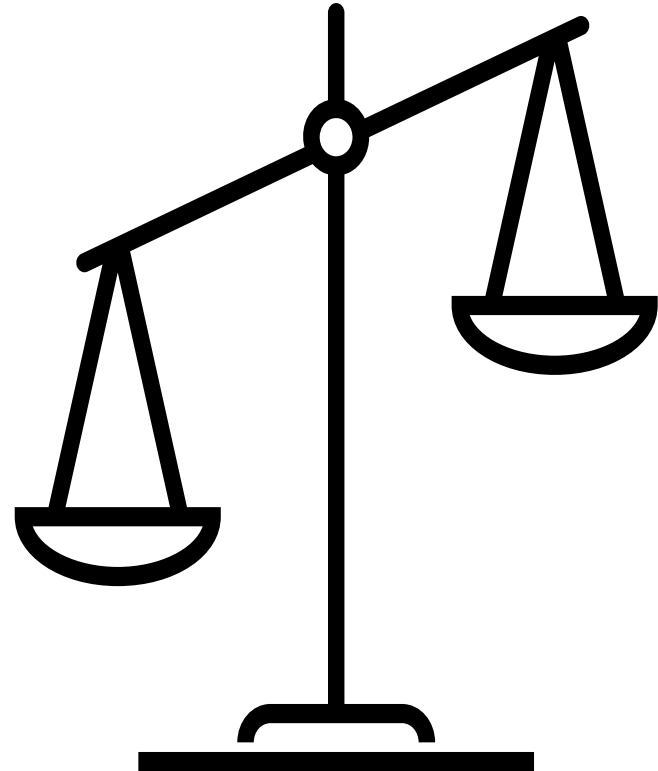
„The right of everyone to timely access to affordable, preventive and curative care of good quality is one of the key principles.“

Key problems

- Persisting Disparities (figures from 2019):
 - Public resources spent on healthcare range from 3% of GDP in Cyprus to 9.4% of GDP in Germany
 - Percentage of total healthcare expenditure spent on CVD range from 3% in Sweden to 19% in Hungary
- Underfunded healthcare systems face shortages in health care provision and medicinal products. They lead to higher out-of-pocket payments from patients.

Key problems

- (Growth in) voluntary and occupational health insurance may **increase inequalities**
- Several population groups have significant difficulties in accessing health care: **low income, women, ethnic minorities, migrants**



Political commitment needed

Deutscher Herzbericht 2020



In Zusammenarbeit mit



Herausgeber

Deutsche Herzstiftung 

Heart Reports/statistics (valid data to prove inequalities)

Morbidität ausgewählter Herzkrankheiten in den Bundesländern

Land	ischämische Herzkrankheiten		davon: akuter Myokardinfarkt		Herzklappenkrankheiten		Herzrhythmusstörungen		Herzinsuffizienz	
	absolut	pro 100.000 Einw.	absolut	pro 100.000 Einw.	absolut	pro 100.000 Einw.	absolut	pro 100.000 Einw.	absolut	pro 100.000 Einw.
Baden-Württemberg	69.961	605	26.090	224	12.401	103	53.405	454	51.776	429
Bayern	90.280	656	30.821	223	14.589	103	69.174	494	75.854	534
Berlin	31.207	880	7.690	217	5.063	136	19.911	542	17.062	471
Brandenburg	22.668	724	7.253	232	3.936	119	19.035	605	18.264	563
Bremen	3.556	501	1.766	248	647	86	3.057	410	2.934	392
Hamburg	9.241	535	3.647	209	1.749	96	8.713	490	8.215	455
Hessen	42.302	636	15.018	225	6.885	100	33.828	500	32.624	471
Mecklenburg-Vorpommern	16.013	809	4.714	238	2.515	121	11.034	553	13.567	654
Niedersachsen	57.483	647	21.633	243	9.819	106	48.638	540	46.112	495
Nordrhein-Westfalen	157.207	817	47.649	246	23.968	119	119.921	612	106.435	526
Rheinland-Pfalz	33.938	744	11.173	243	5.227	111	25.620	557	24.432	511
Saarland	9.546	805	3.230	270	1.134	94	6.206	519	6.969	555
Sachsen	25.344	502	9.506	188	4.852	89	23.043	444	29.222	521
Sachsen-Anhalt	24.169	860	6.721	240	3.201	107	16.235	574	19.213	637
Schleswig-Holstein	24.185	721	7.609	228	4.136	118	18.791	555	15.401	442
Thüringen	18.520	688	6.142	228	3.023	107	14.762	543	18.276	644
Deutschland	635.620	699	210.662	231	103.145	108	491.373	531	486.356	510

Political commitment needed

Fight for national CVD plans

(e.g. campaign „Beherzt handeln“ – „take decisive action“ with all relevant CVD stakeholders and politicians)

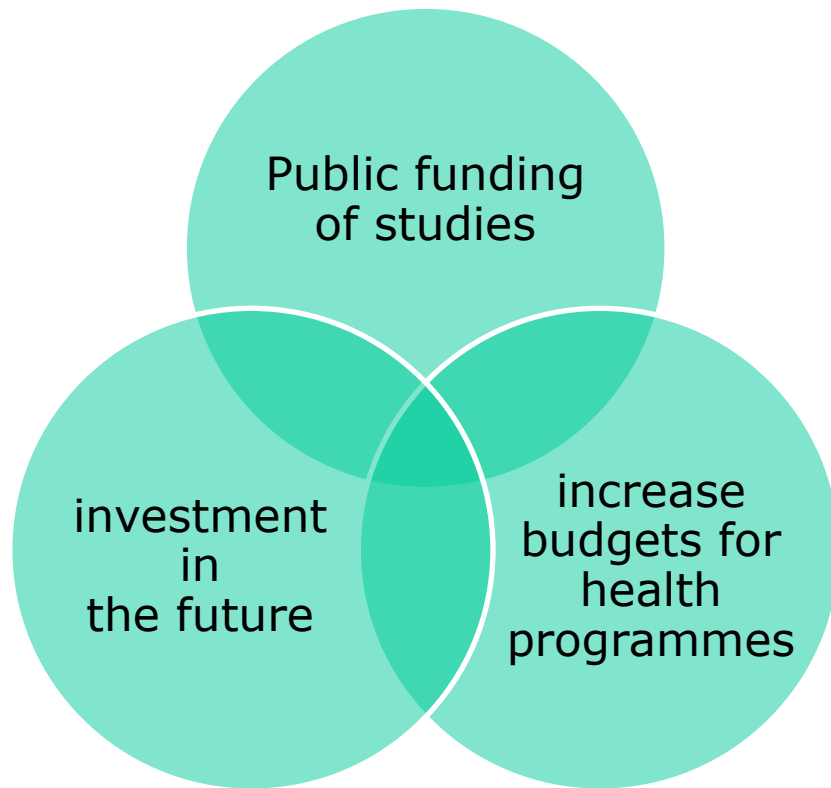


Sie möchten Abgeordnete/r
der **Herzen** sein?
Das würden wir gerne
wörtlich nehmen.

Prof. Dr. Claudia Schmidtke
patient commissioner of the federal government

 Deutsche
Herzstiftung

Political commitment needed



Ideal scenario

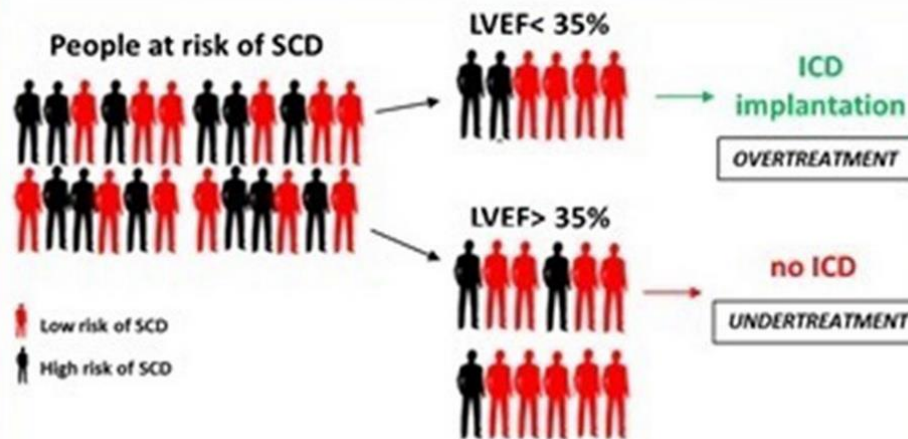
- the clinical trials agenda and **priorities are driven by patients and societal needs** (the industry will be the enabler instead of the driver)
- **optimal use of data** from various sources, including electronic health records, registries, and re-use of data from past studies

Individual vs. one size fits all

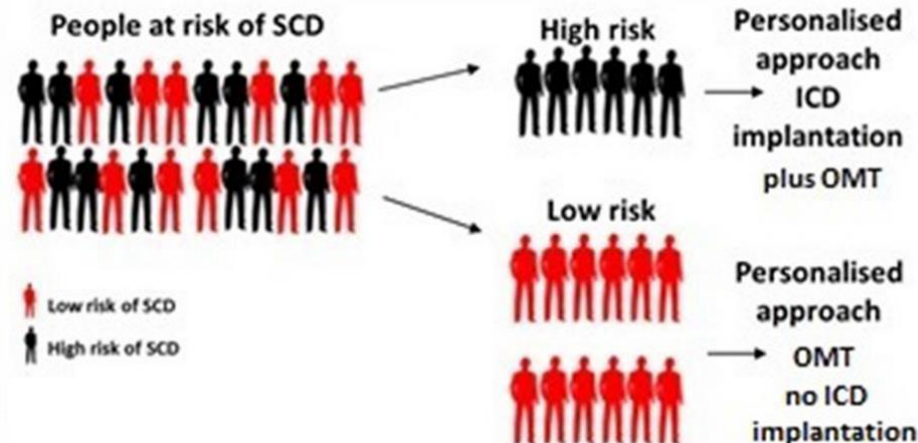
More research for tailored therapies (example PROFID)

Ideal result of PROFID

Current clinical guidelines:



After PROFID:



<https://profid-project.eu/>

What are the patients' needs?

- Investment in **cardiovascular conditions in children** (financial interests should not lead research)
- Flexibility to ensure best treatment (legal responsibility, off-label use)
- Investment in cardiovascular innovation:
match discovery science to unmet patients' needs, considering the burden of disease, patient-relevant clinical and **quality-of-life endpoints/limitation of side-effects**

What are the patients' needs?

Faster access to
new medicines
and medical
devices

Meaningful
involvement in
studies

Ensure drug
production sites in
Europe
(avoid
shortages)

What are the patients' needs?

- Electronic patient records to ensure correct treatment in emergency cases; owner of data, **safety**
- Patient registries, Real World Data
- Digital apps/telemedicine as a standard add-on
- Digitalisation (online programmes, arranging appointments) where appropriate as a complementary model (**respecting non-digitalised patients**)

What are the patients' needs?

- (Administrative/supporting) tasks to be shifted, new professions to be created (not only doctor-centred, example heart nurse)
- Modernising medical training
- **More time for patient-doctor interaction**

What are the patients' needs?

Better interdisciplinary networking

Programmes beyond rehabilitation as secondary prevention (including psychological help)

Judging the individual not the average (e.g. work capacity/degree of disability)

Faster access to specialists/reduce waiting lists

Shared-decision making

What are the patients' needs?

- Health policy as a service of public general interest (not driven by commercial interests)
- Political plans to modernize healthcare system are urgently needed, but often not realistic (example: HCP are supposed to use devices/structures that are not available yet)
- Health care policy should consider all stakeholders to ensure a **safe, reliable and patient-centred health care**

Role of patients' organisation

- Strong alliance with other like-minded societies and foundations (e.g. EHN/Non Communicable Disease Alliance, Beherzt handeln)
- Contact point/patient expert for politicians
- Inform/train the patient
- Represent the **real** patients' needs

Listen to the patients' voice whenever it is
ABOUT THE PATIENT!

Thank you!

Any questions?

dehn@herzstiftung.de