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Why collecting data matters for patients

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The Positive Council

- Expert association with 15 members engaged in defending rights and interests of people living with HIV
- >75% live with HIV
- Close collaborations with Swiss AIDS Federation
- Mission: Optimise conditions of life on people living with HIV, optimise medical care, remove legal & social barriers, support scientific research

Priorities

- Medical: Collaboration with SHCS
- Legal: private insurances
- Care: migrants

Priority SHCS – why?

- High standard of care (SoC) in CH due to 25 years of excellent research by SHCS – “know thy patient”
- Development SoC requires SHCS – we want to document why
- Patients collaborate with European cohort umbrellas
 - Penta, COHERE, Eurocoord, ART-CC
 - this collaboration can be improved
- SHCS long-term funding and functioning requires patient support

How

- Summarising published studies in lay friendly language
- Secure long-term funding for SHCS

A chronic disease with engaged patients

- Denver Declaration 1983 – people with AIDS from California & NY meet in Denver ▪ Denver Principles
 - We recommend that people with AIDS...
 - Be involved at every level of AIDS decision-making and specifically
 - Be included in all AIDS forum with equal credibility as other participants, to share their own experiences and knowledge

“Nothing about Us, Without Us”

A chronic disease with rapid changes

- 1981: First reported AIDS case
- 1982: FDA receives first IND
- 1983: HI-virus discovered
- 1984: CDC confirms HIV as causing AIDS
- 1987: AZT approved
- 1991: ddC & ddI approved
- 1994: start of first triple therapy (HAART)
- 1992 – 2013: 21 years, >30 new antiretroviral drugs
- 2011: Impact of treatment on prevention recognised
- Most drugs via accelerated approvals ▪ toxicities from 1997
- Many lives saved with expanded access programmes
- SHCS ready since 1987 to address research questions



Key factors for success

- ✓ Well documented misery 1987-1996
- ✓ Equally well documented turn of tide from 1996
- ✓ Fosters collaboration: University centres, smaller hospitals & private practitioners collaborate & share data access
- ✓ Make it work: strong internal project scrutiny, pay on delivery
- ✓ Quality: high quality output encouraging others to collaborate
- ✓ Cohort questionnaire: fosters doctor-patient communication & establish long-term trust
- ✓ Representative cohort, including data from 18'000 patients
- ✓ 70% of prescribed ARV's in CH prescribed by SHCS clinics
- ✓ Most side effects understood / under control
- ✓ Evaluate different treatment strategies



Globally acknowledged output

- ✓ Number of publications per year
 - 35/y own
 - 25/y collaborations
 - 4'000 citations per year
- ✓ 90% of patients achieve suppression within 12 months, including drug users
- ✓ Impact on prevention
- ✓ Long-term success: most patients now eligible for life insurances up to 20 years
- ✓ Participating patients have a well documented electronic record



Future issues

- ✓ Ensure long-term funding and patient's trust
- ✓ SHCS annual budget: 3'200'000
- ✓ Patients seen per year: 8'400
- ✓ Annual cost of care per patient: 20-25'000 CHF
- ✓ SHCS cost per patient/y: 381 CHF, 1.5% of cost of care
- ✓ Collaborate effectively with larger cohort umbrellas
- ✓ Communicate better with participants and larger public
- ✓ Use cohort data to support HTA

Thanks

- Prof Huldrych Günthard, SHCS President