

From Research to Clinical Care and back:

Building an ICT infrastructure

Harm Slijper

Xpert Clinic
een equipe zorgbedrijf



Clinical care vs. Clinical research

- › Everywhere
 - › Paid for
 - › Patients available
 - › Healthcare professionals
 - › Data collection when needed
 - › Rare
 - › Funding
 - › Selected patients
 - › Researchers
 - › Systematic data collection
-
- › Interest in knowing the effect of an intervention
 - › Wouldn't it be nice to bring them closer together?

History

- › Making science more manageable
- › Growing need for studies in a clinical setting
- › The team (2009-2013):
Erasmus MC (Public Health Care, Plastic Surgery, Rehabilitation)
Xpert Clinic & Hand Therapie Nederland

The context:

- › Little money
- › No resources
- › Patients/ respondents available
- › Healthcare professionals involved
- › Some structured process of treatment (appointments)
- › Support from management
- › Commitment to reach consensus

An opportunity?

What we did:

- › Collaborate
- › Built open-source software
- › Built on existing products
- › Let healthcare professionals participate
- › Let the patient participate

- › Develop a 'concept' to capture changes in health over time

Some conditions.....

- › Always, everywhere
- › Safe, accountable and secure
- › Highly customizable (DIY)
- › Multiple organizations
- › Patient/ respondent management
- › Integrates with the healthcare process
- › Intuitive, easy to use

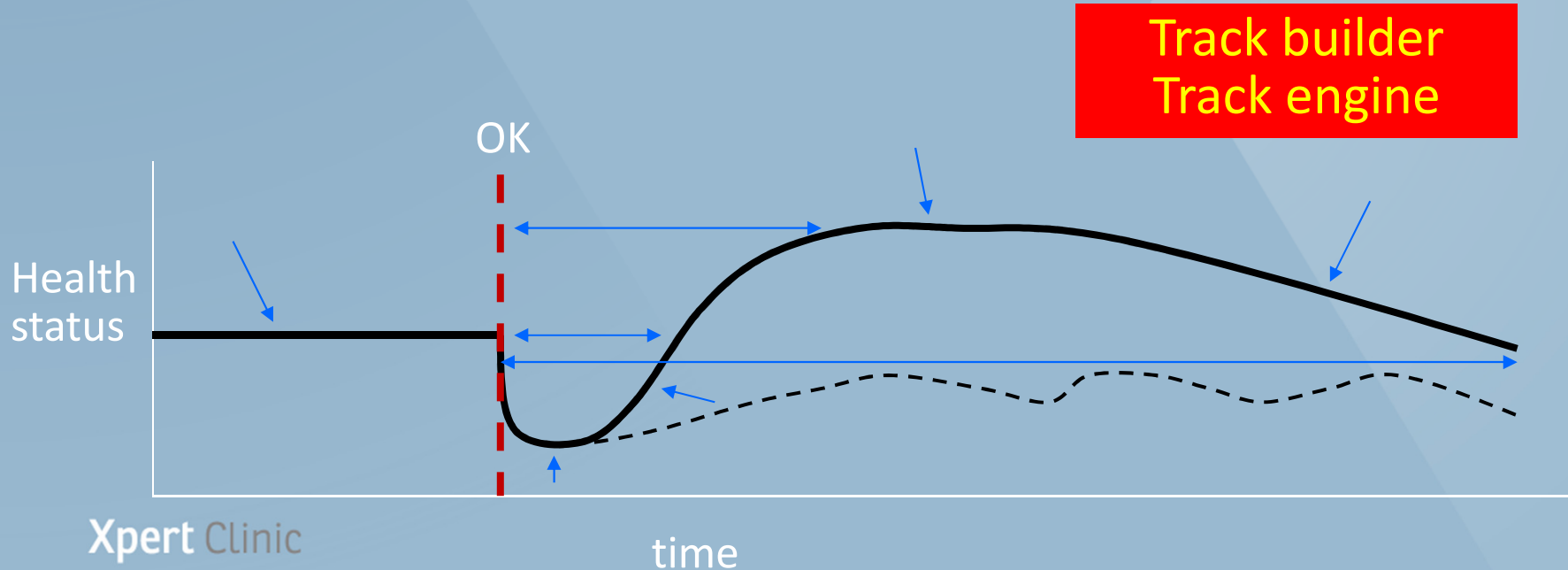
Existing products

- › Clinical trial software → for researchers
- › Questionnaire packages → for respondents
- › EPD's → for healthcare workers

We wanted all three integrated.....

Core concept: Measurement Track

- › Track
 - › Round
 - › Field
 - › Questionnaire/ form
- Token
 - Respondent
 - Organization/ study



Example:

Surveys in Duim Kort track

	Survey	Details	By	Description
preview	Behandeldatum	Intake	Zorgverlener	Wanneer is de OK-dag of de start van de conservatieve behandeling?
preview	Intake / vervolg Duim kort	Intake	Zorgverlener	Deze vragenlijst wordt afgenomen aan het begin van het behandeltraject bij een behandeling aan de du
preview	VAS pijn, functie en tevredenheid hand	Intake	Patiënt	Pijnschaal en hand functie
preview	MHQ: Handfunctie	Intake	Patiënt	
preview	PSFS: Activiteiten	Intake	Patiënt	Patient Specifieke Klachten
preview	VAS pijn nabellen	1 dag	Zorgverlener	Pijnschaal (0-10) voor bij het nabellen.
preview	VAS pijn, functie en tevredenheid hand	6 weken	Patiënt	Pijnschaal en hand functie
preview	MHQ: Handfunctie	6 weken	Patiënt	
preview	Return to Work	6 weken	Patiënt	Door middel van deze vragenlijst wordt inzicht verkregen in het ziekteverzuim a.g.v. uw aandoening
preview	Tevredenheid resultaat behandeling	6 weken	Patiënt	Korte vragenlijst voor patient over tevredenheid en resultaat behandeling.
preview	PSFS: Activiteiten	6 weken	Patiënt	Patient Specifieke Klachten
preview	VAS pijn, functie en tevredenheid hand	3 maanden	Patiënt	Pijnschaal en hand functie
preview	MHQ: Handfunctie	3 maanden	Patiënt	
preview	Return to Work	3 maanden	Patiënt	Door middel van deze vragenlijst wordt inzicht verkregen in het ziekteverzuim a.g.v. uw aandoening
preview	Tevredenheid resultaat behandeling	3 maanden	Patiënt	Korte vragenlijst voor patient over tevredenheid en resultaat behandeling.
preview	PSFS: Activiteiten	3 maanden	Patiënt	Patient Specifieke Klachten

Setting up your study/ site

1. Install GemsTracker and for instance LimeSurvey on a server
2. Built your questionnaires (set and link questions)
3. Built your tracks (set and link questionnaires)
4. Tune your site (layout, overviews, roles, groups)
5. If needed: couple to EPD

<http://gemstracker.org>

Xpert Clinic



The screenshot shows the Gemstracker website homepage. The header features the 'Gemstracker' logo in orange and a navigation menu with links for Home, News, General information, Features, Demo, and Download. The main content area is divided into three columns. The left column, titled 'Home', contains a paragraph describing Gemstracker as a software package for (complex) distribution of questionnaires and forms during clinical research and quality registrations in healthcare. It lists several features: Extensive patient/ respondent management, Compose your own measurement track from your questionnaires and forms, Large number of data overviews: per patient/respondent, track, questionnaire, rounds, etc, Multi-center functionality, User friendly interfaces, Elaborate rights management, and Extensive security and logging possibilities. Below this, it states that Gemstracker is developed at the Erasmus MC, Rotterdam in collaboration with several partners. The middle column, titled 'Important pages', lists links for Demo, Documentation, API, and Bugtracker. The right column, titled 'Latest news', lists two news items: '1.6 released March 20, 2013' and 'Presentation on Gemstracker March 19, 2013'. Below this, the 'Commits' section lists a 'New commit' from April 19, 2013, with a detailed description of a fix for disappearing round editor titles. At the bottom of the page, there is a 'Log in' link.

Patient management

Patients

New

Overview

Project

Extreme Values

Setup

Pulse Setup

Track Builder

Export

Your account

Token

Contact

Pulse Manual

Patients

Xpert Clinic

	Skalpell nr Intramed nr Organization	Name Location	Current track [Current round] Description PP Treatment	Changed by Changed on	
show	821112-A006 Xpert Clinic	Prooijen, R.D. van Zeist	Duim Kort [Intake] Links Chirurgisch Hand- en polschirurgie / Adams procedure	Slijper, Harm Oct 8, 2012	edit
show	731130-A002 Xpert Clinic	Slijper, Harm Eindhoven	handenpolschirurgie: voortraject [preconsult] Hand- en polschirurgie / Brunelli	Slijper, Harm Mar 8, 2013	edit
show	670628-A002 Xpert Clinic	Haseth, R. Rotterdam	handenpolschirurgie: voortraject [preconsult] Hand- en polschirurgie / Carpaal tunnel release	Slijper, Harm Mar 5, 2013	edit

1 to 3 of 3

[New](#)

Patient overview

Patients

- New
- Show**
- Personal Page
- Personal Page Setup
- Edit
- Tracks
- Surveys
- Export archive
- Delete
- Overview
- Project
- Extreme Values
- Setup
- Pulse Setup
- Track Builder
- Export
- Your account
- Token
- Contact
- Pulse Manual

Patients > Show

Patient: Personal Page Edit

Tracks (1) newest: Duim Lang [Rechts Chirurgisch Primair] is at: 3 maanden Add Track

	Track	Description	Start	Progress	Assigned by	Track	Description	
show	Duim Lang	Rechts Chirurgisch Primair	21-01-2013	14 of 36	Michel , Mila	Duim Lang	Rechts Chirurgisch Primair	edit

Surveys (4) Add for Patient Add for Staff

Answered tokens (18)

Tokens to do (2)

	Track [Description]	Survey [Round]	Assigned to	Status	
+	Duim Lang [Rechts Chirurgisch Primair]	Handchirurgie Vragenformulier [Handmatige invoer]	Equipe Invoerder	Always valid	fill in
+	Duim Lang [Rechts Chirurgisch Primair]	Anesthesie Xpert Clinic Vragenformulier [Handmatige invoer]	Equipe Invoerder	Always valid	fill in

Missed (1)

Appointments (4)

Intake forms and Anaesthesia (2)

Compliance







Duim Kort (all organizations)

Track start Track end » from until

(all fillers) (all locations)

Search

Legend

-  Valid from date unknown
-  Valid from date in the future
-  Open - can be answered now
-  Answered
-  Missed deadline
-  Token does not exist

	Patient nr	Start date	Intake					OK check	1 dag	6 weken					3 maanden					Handmatige invoer		controle	End date				
			Be	In	VA	MH	PS	In	VA	VA	MH	Re	Te	PS	VA	MH	Re	Te	PS	In	Ha	An		ZK			
show	810805-A003	16-11-2011																									
show	600909-A005	17-11-2011																									
show	600222-A014	21-11-2011																									
show	501020-A003	23-11-2011																									
show	531105-A006	24-11-2011																									

<< First | < Previous | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Next > | Last >>

1 to 5 of 931

Export survey answers

Respondent
id's

Not patient nr, but respondent id as exported here.

Tracks

Duim Kort

Survey

VAS pijn, functie en tevredenheid hand

1 records found.

Organization

- Diakonessenhuis
- Equipe Personeel
- ErasmusMC Revalidation & Plastic Chirurgie
- Expertise @ Xpert Clinic
- Helder Kliniek
- Schön Klinik
- Velthuis Kliniek
- Xpert Clinic

Toggle

Export to

SPSS

Which file

- syntax
- data

You need both a syntax and a data file. After downloading, open the syntax file in SPSS and modify the line `/FILE="filename.dat"` to include the full path to your data file. Then choose Run -> All to execute the syntax.

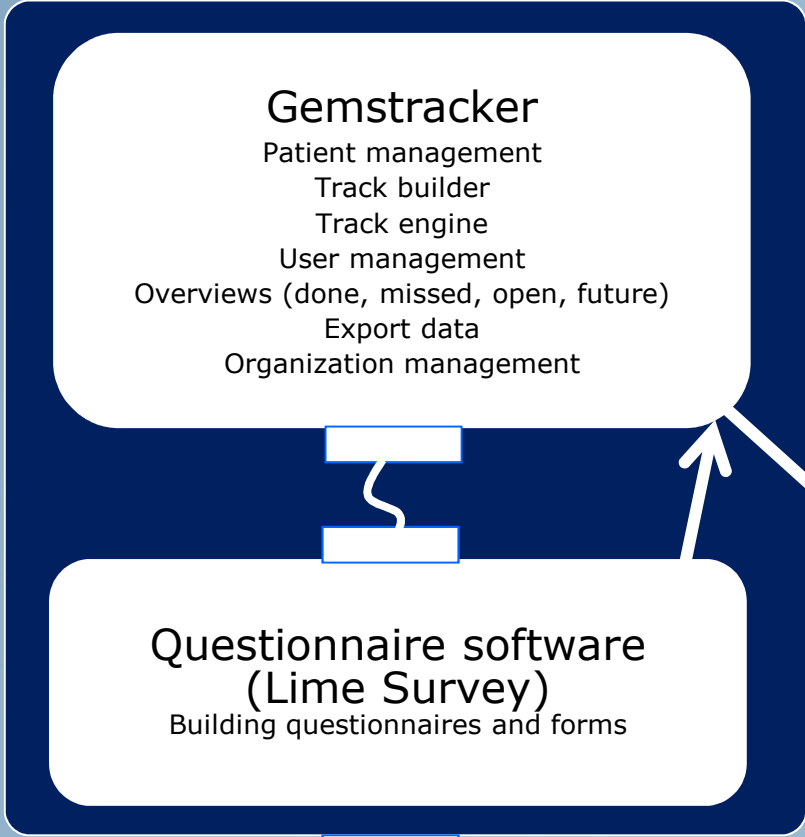
Export

Research & clinical care integrated

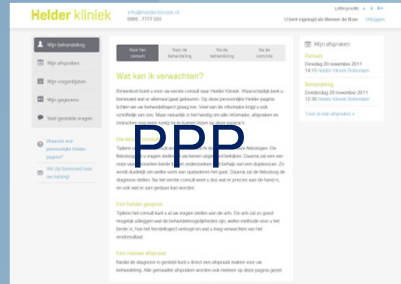
- › All patients to the 6 clinics participate in data-collection: Tracks for everyone!
- › Integrated with EPD
- › Connected to data warehouse for analysis
- › Personal Patient Page: My Xpert Clinic
- › Extreme value detection

Why?

- › Transparency about medical and business performance
- › Knowledge to improve performance
- › Better contracts with health insurance companies
- › Centers of excellence: Scientific output, medical training



Process



Call center

Baseline questionnaires/ forms

Track Assignment 1 out of 8

Consult

Pain monitoring, Post-treatment questionnaires

Treatment Information 1 out of 106








Treatment

6 weeks, 3,6,12 months questionnaires/ forms

Rehabilitation Information 1 out of 45

Control

Personal Page

-  My treatment
-  Client instruction
-  My consults
-  My surveys
-  My data
-  FAQ
- Your opinion
- Handforum.nl 

Welcome Mr. Slijper,

Dit is Mijn Xpert Clinic. Hier vindt u alle informatie bij elkaar die u gedurende uw behandeltraject nodig heeft. Alle afspraken bij de arts voor behandelingen en controles vindt u hier terug. Maar u leest ook wat u kunt verwachten tijdens het consult, de ingreep en de herstelperiode. Klik hiervoor op "Mijn behandeling" in het linker menu.

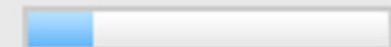
Uw vragenlijsten

Op verschillende momenten tijdens uw behandeltraject vragen wij u om een vragenlijst in te vullen. Op die manier kunnen wij het resultaat van uw behandeling beter beoordelen en u daarmee optimaal behandelen. Het invullen kost wat tijd, maar is dus heel belangrijk. Wij hopen dan ook op uw medewerking!

Open surveys

-  **PSFS: Activiteiten Round: Intake** 
This survey can always be answered.
-  **VAS pijn, functie en tevredenheid hand Round: Intake** 
This survey can always be answered.
-  **MHQ: Handfunctie Round: Intake** 
This survey can always be answered.
-  **VF handenpols V2013** 
This survey can always be answered.

Dupuytren Links Primair Dig1 Dig2



- 0 completed succesfully
- 0 missed survey(s)
- 4 survey(s) to be completed
- 18 future survey(s)

[Show all my surveys »](#)

My consults

Consult handchirurg

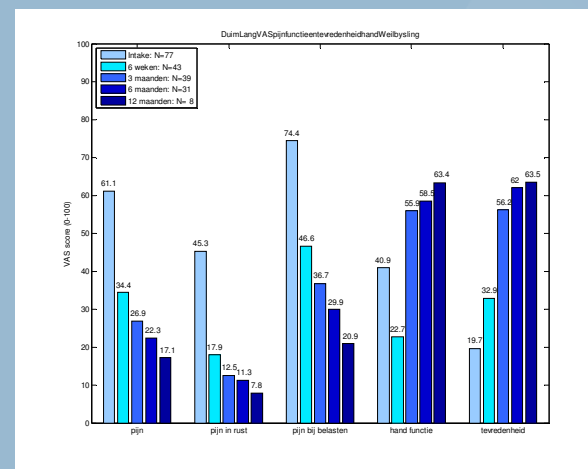
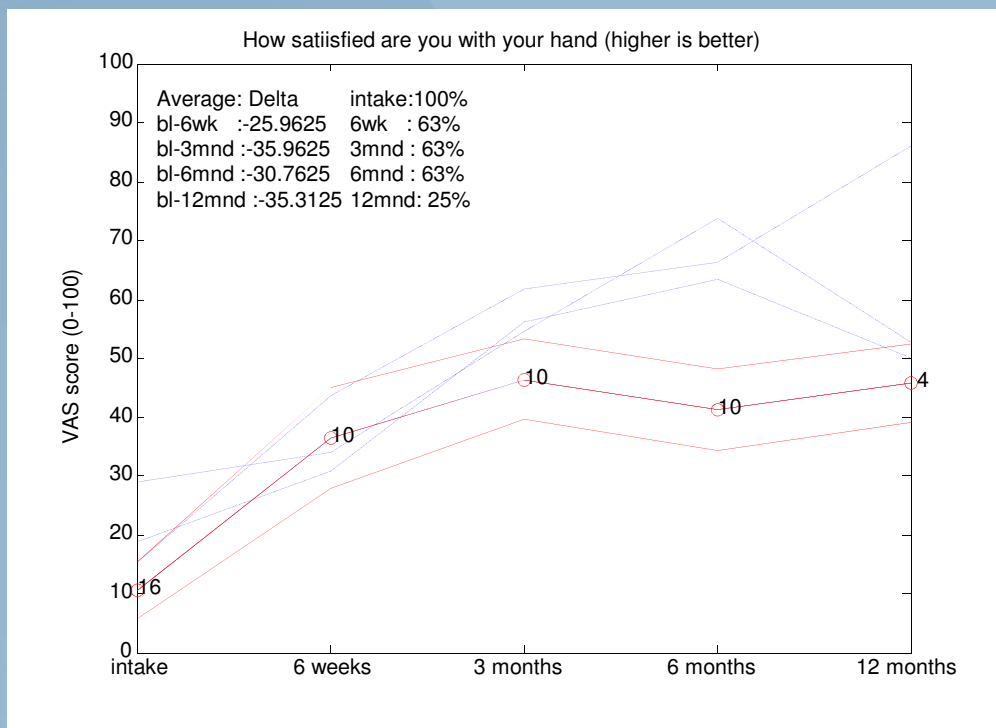
Friday 12 April 2013

13:40 Xpert Clinic Rotterdam

[Show all my consults »](#)

Output

- › Extreme value detection
- › Therapists discuss outcomes with patients
- › Prognosis for every treatment on PPP
- › Scientific studies
- › Surgeon performance dashboard



Patient compliance:

Intake: 65%
6 wks: 50%
3 mnd: 65%
12 mnd: 55%

Therapist compliance:

Intake: 80%
6 wk: 40%
3 mnd: 65%
12 mnd: 50%

In 18 months:

7500 tracks assigned
15.000 e-mails to patients
42.000 filled in questionnaires
24.000 therapist measurements

Take Home Messages

- › It is possible to bring clinical care and clinical research closer together, with benefits for patients & healthcare professionals
- › Involving patients and health care professionals in data-collection requires that collected data is relevant for them.
- › The concept of 'Track' fits many research needs
- › Accountable data collection: a must!
- › Upfront investment for your study is worth it!
- › Special statistics is needed for analysis of data: Next talk

Open source software package available: <http://gemstracker.org>

A Gemstracker service will be offered through ZKN for PROMS.