



**Patientenplatform
Sarcomen**

Patient Forums: Telling the Patient Story and its Impact on Healthcare

NEW HORIZONS 2017

October 3, 2017

Gerard van Oortmerssen



Erasmus Medical Center Rotterdam Patient Participation Project

- **Design of healthcare pathway**
- **Research agenda**
- **12 GIST and Sarcoma patients, 12 specialists**
- **Additional research by Patientplatform**
Sarcomas: Value assessment
- **Choose from a list of around 100 different words (values)**



Value assessment

- What is really important for you as a person
- Which values best describe the current treatment situation
- Which values would describe your ideal treatment situation

Gerard van Oortmerssen

Richard Barrett's method

Seven Levels of Personal Consciousness



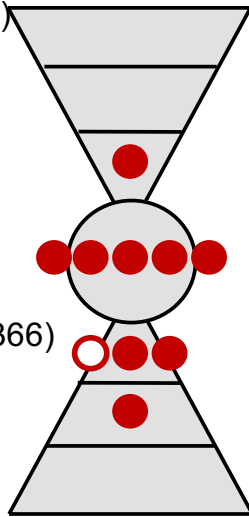


The Methodist Hospital Houston

THE JOURNEY TO FULL SPECTRUM

Current Culture 2001 (1695)

1. patient satisfaction (609)
2. cost effectiveness (551)
3. **continuous improvement** (532)
4. being the best (495)
5. **accountability** (487)
6. **commitment** (487)
7. bureaucracy (411) (L)
8. **continuous learning** (366)
9. achievement (355)
10. **teamwork** (349)

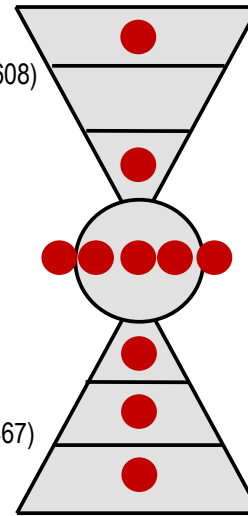


PL = 9-1
 IROS (P) = 2-2-5-0
 IROS (L) = 0-0-1-0

5 Matches

Current Culture 2002 (6814)

1. **accountability** (2815)
2. **patient satisfaction** (2608)
3. **being the best** (2231)
4. **continuous improvement** (2067)
5. **commitment** (2028)
6. cost effectiveness (1874)
7. **compassion** (1724)
8. **teamwork** (1676)
9. achievement (1490)
10. continuous learning (1467)

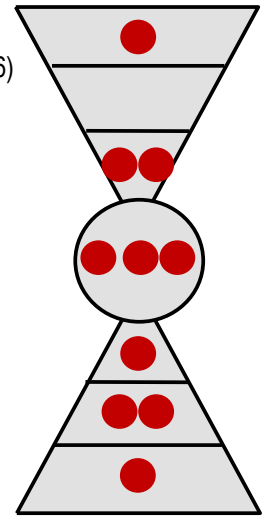


PL = 10-0
 IROS (P) = 2-3-5-0
 IROS (L) = 0-0-0-0

7 Matches

Current Culture 2003 (7502)

1. **accountability** (3352)
2. **patient satisfaction** (2956)
3. **being the best** (2376)
4. **commitment** (2270)
5. **compassion** (2087)
6. **continuous improvement** (2066)
7. **integrity** (1921)
8. **teamwork** (1878)
9. cost effectiveness (1816)
10. **respect** (1662)



PL = 10-0
 IROS (P) = 2-4-4-0
 IROS (L) = 0-0-0-0

9 Matches

LEGEND		
<u>Underline</u> = PV & CC match	P = Positive	I = Individual
Red = PV, CC & DC match	L = Potentially Limiting	R = Relationship
Red = CC & DC match	(hollow dots)	O = Organizational
Blue = PV & DC match		S = Societal



Results: Medical Professionals (10)

Level	Personal Values	Current Cultural Values	Desired Cultural Values
7			
6			
5			
4			
3			
2			
1			
	<i>reliability</i> 7 3(R)	<i>involvement</i> 6 5(I)	<i>collaboration across teams</i> 5 6(O)
	<i>collaboration</i> 6 5(R)	professionalism 6 3(O)	<i>involvement</i> 5 5(I)
	efficiency 5 3(I)	bureaucracy (L) 5 3(O)	<i>reliability</i> 5 3(R)
	enthusiasm 5 5(I)	<i>collaboration across teams</i> 4 6(O)	continuous improvement 5 4(O)
	being liked (L) 4 2(R)	<i>collaboration</i> 4 5(R)	dialogue with patients 5 6(O)
	clarity 4 5(I)	<i>teamwork</i> 4 4(R)	information sharing 5 4(O)
	humor/fun 4 5(I)	<i>patient satisfaction</i> 4 2(O)	<i>teamwork</i> 5 4(R)
	performance-oriented 4 3(I)	trust 4 5(R)	<i>honesty</i> 4 5(I)
	ambition 3 3(I)	<i>reliability</i> 3 3(R)	open communication 4 2(R)
	<i>involvement</i> 3 5(I)	goal oriented 3 4(O)	<i>patient satisfaction</i> 4 2(O)
	perseverance 3 4(I)		
	<i>honesty</i> 3 5(I)		
	innovation 3 4(I)		
	positive attitude 3 5(I)		

Cultural entropy:
Current culture:
12%

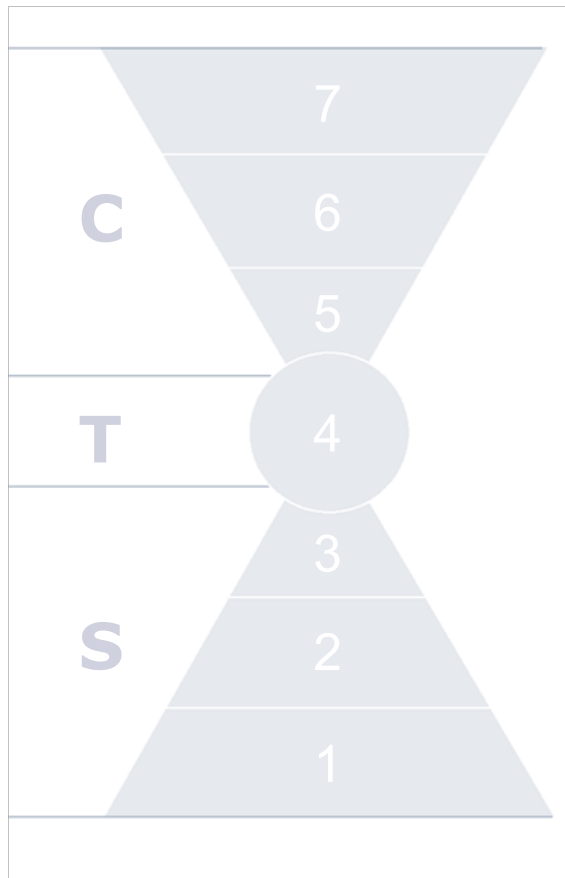
Zwart onderlijnd = PW & HC
Oranje = PW, HC & GC
 Oranje = HC & GC
 Blauw = PW & GC

P = Positief
 L = Mogelijk beperkend (witte cirkel)

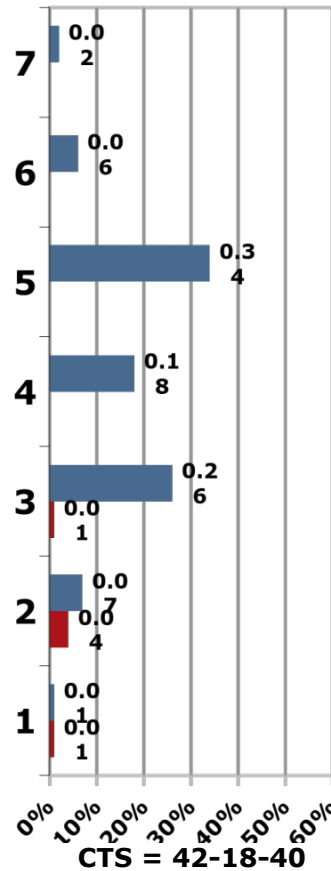
I = Individueel
 R = Relatie
 O = Organisatie
 S = Samenleving



Results: Medical Professionals (10)

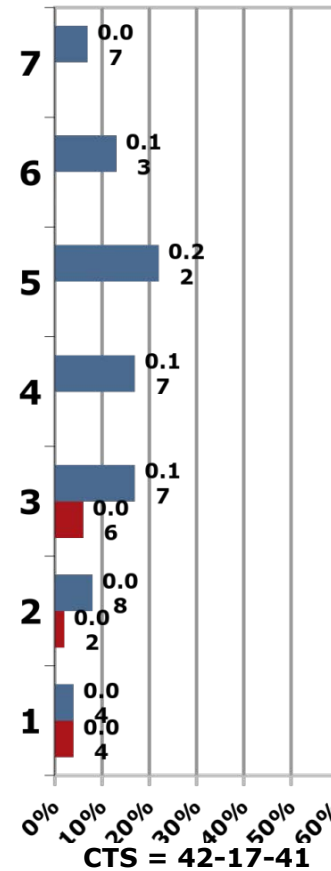


Personal Values



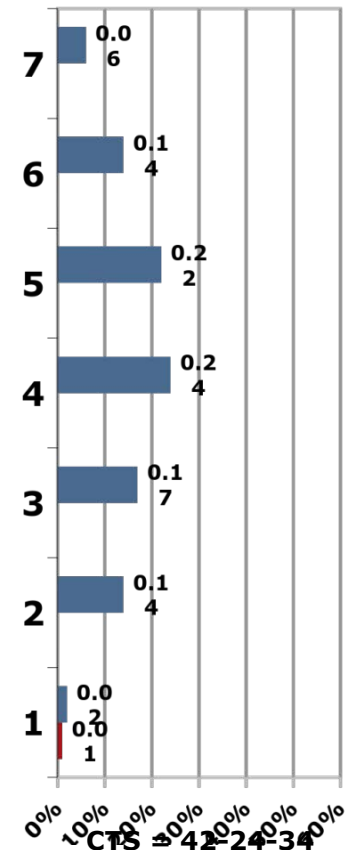
Cultural entropy = 6%

Current Cultural Values



Cultural entropy = 12%

Desired Cultural Values



Cultural entropy = 1%

C = Algemeen belang
T = Transformatie
S = Eigenbelang

■ Positieve waarden
■ Mogelijk beperkende waarden



Medical Professionals (10)

Cultural Entropy Report

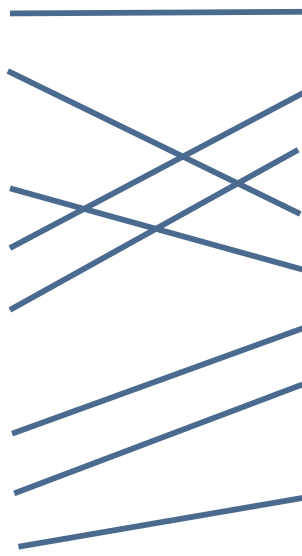
Level	Potentially limiting values (# votes)	Cultural Entropy %
3	bureaucracy (5) hierarchy (1)	6% of total votes
2	internal competition (1) kingdoms (1)	2% of total votes
1	control (2) short term orientation (1) caution (1)	4% of total votes
Total		12% of total votes

Desired Cultural Values

Medical professionals



Patients

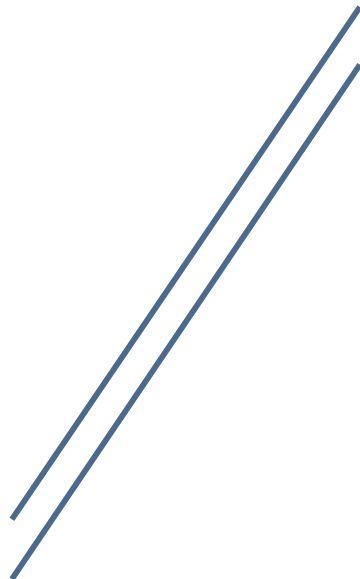
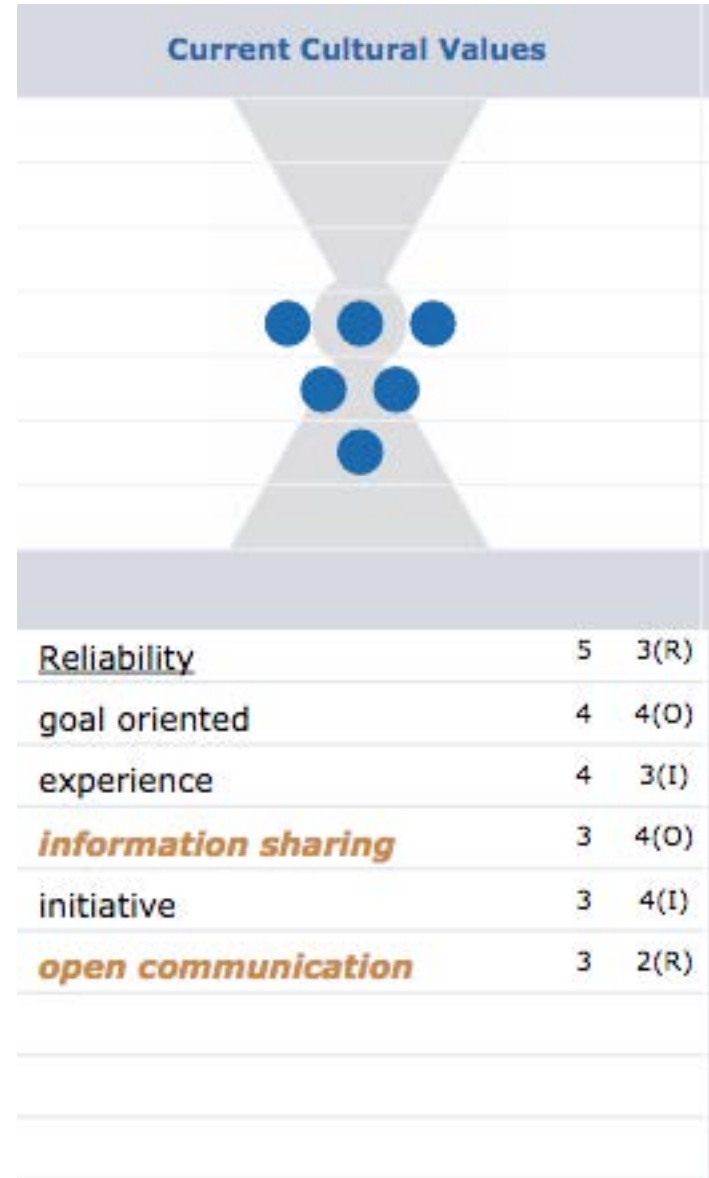


Current Cultural Values

Medical professionals



Patients



Value Jumps

Value

Med.prof.

Patient

Collaboration across teams and departments

1

4

Dialogue with patients

3

4

Information sharing

4

4

Discussie fora

Patients share detailed medical information:

caregiver for mother dx with GIST 12/31/12

31x19x9 cm primary tumor removed 12/12/12

400 mg gleevec 1/15/13 to 12/6/13

Recurrence and removal of 3 masses from the omentum (3.5 to 4.4 cm) on 12/6/13

Sutent 25 mg. since 1/15/14 37.5 mg. since 8/14 (failed Sutent 6/15)

Sorefinib (naxavar) 7/3/15

more tumors removed 7/13/15


Votrient 9/4/15 to 12/30/15

50 tumors removed 1/16/16'

Wildtype Gist NO Kit or PDFRA mutation, SDH intact

Discussion fora:

- Information on:
 - Development of disease, treatment, side-effects
 - Strategies to cope with side-effects
 - Adherence to therapy
 - Co-morbidity: bad-luck or is there relationship?
 - Quality of life




GIST Support International
Public Group

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 Write something...


RECENT ACTIVITY


 **Tara Berlingieri Garcia**
19 hrs · Williston Highlands, FL, United States


Well gister peeps ct scan show no new growth everything else the same lab work good. Keeping me on 800 gleevec. Dr is scheduling a petscan to look deeper into the tumors. So i am thankful and blessed but i wont lie i am a little disappointed

Like Comment Share

 Jetty Hamersma-Nicolai, Marina Symcox and 19 others

 **Elaine Cummings** Why?
Like · Reply · 19 hrs

 **Tara Berlingieri Garcia** Are u asking why i am disappointed. Well i guesa i had been feeling pretty darn good for the most of the past 2 mos i thought for sure the results would show more shrinkage. You know we all hope for a miracle.
Like · Reply · 1 · 19 hrs


 **Elaine Cummings** Yes I have been trying too, but it just stopped at 18 cm and they will not operate yet. But you do not give up because I do believe God heals. ❤️
Like · Reply · 4 · 18 hrs

View more replies

ADD MEMBERS ⓘ

+ Enter name or email address...

MEMBERS 2,431 Members (16 new)



Invite by Email

DESCRIPTION

GIST Support International (GSI) is an all-volunteer organizatio... See More


TAGS

Cancer · Sarcoma · Gastrointestinal stromal tumor

CREATE NEW GROUPS

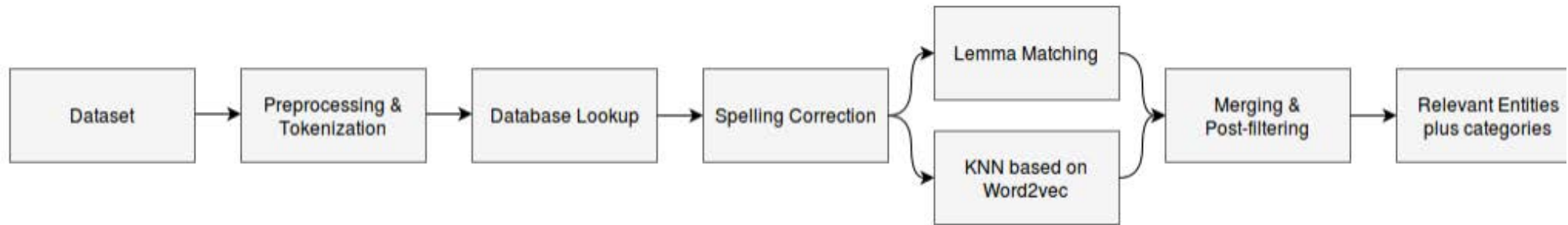
Groups make it easier than ever to share with friends, family and teammates. [Create Group](#)

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Analysis of discussions



UMLS: thesaurus with medical terms (NHI) and other databases (DBPedia)

Translation in case of Dutch or other languages

Word2Vec: semantic relationships

Example

Normal dose of imatinib for GIST patients is 400 mg per day.

In case of progression: increased to 800 mg per day.

In one hospital policy was to advise patients to take full 800 mg at dinner

Question: would it be better to split the dose?

Based on forum discussion analyses: yes, most patients experience less side effects when splitting the dose.

Based on result, policy of hospital was changed.

Something else was found: patients reported that taking the medicine with dark chocolate greatly diminishes nausea.

Example: research agenda

- Patients participate in agenda setting for research in university hospital
- Longlist of topics was composed on basis of analysis of (inter)national discussion fora: What is important for patients?
- Longlist was used to consult patients through web survey: What are your priorities and why?
- 75 patients responded
- 3 topics were selected and are now worked on by a PhD student
- 1 topic could be addressed on basis of existing knowledge, now published in magazine of patient organisation

Further development

- Gaining experience, fine-tuning of software
- Building experience: project with 4 other cancer patient organisations in Netherlands, combine with surveys, build experience and improve algorithms
- Further development of text mining: quantification, statistical analysis, validation: clinical testing of hypotheses (PhD project)
- Combining informal knowledge with:
 - Pubmed, curated medical knowledge
 - Registries with structured medical patient data
- Chatbot: intelligent conversational interface to assist users

Thank you!

Search bar

in BVN



Search

minder detail meer detail

How the project started

- 2005 my nearest colleague got diagnosed with GIST - he died in 2010
- 2007 my brother was diagnosed with GIST
- 2010 I was diagnosed with GIST, same rare mutation as my brother
- 2013 found another relative with GIST
- 2016 my (and my colleague's) secretary diagnosed with GIST