



Hoe kunnen patiënten ècht betrokken worden

Perspectief van de Sponsor

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DCTF Jaarcongres Ede | 05 Oktober 2016

Betsy Gross, *Lilies and Carp*
Artwork from The Creative Center

Hoe kunnen clinical trials anders?

Participants tell us how the clinical trial experience can be improved

- ✓ Trials not accessible to where they live

70% do not live near research center

- ✓ Treated as subjects, not people

“Be efficient with my time, manage my expectations”

- ✓ No follow-up or communication of results

“I’d like a Thank You and to know my participation was important”

PATIENT

SPONSOR

TOEGANG

RECRUTERING

GOEDE ERVARING

RETENTIE

BETROKKENHEID

INZICHTEN

Breng de Trial naar de Patient

o.a. mHealth technologie,
lokale/thuis-visites & assessments

Verbeter de Deelnemers Ervaring

o.a. patient-gericht trial design en
feedback vragen

Patient Gericht Trial Design

- Genereren van unieke inzichten mbt trial design en uitvoering
- Idee/Probleem – Demonstratie – Opschalen – Routinematig toepassen

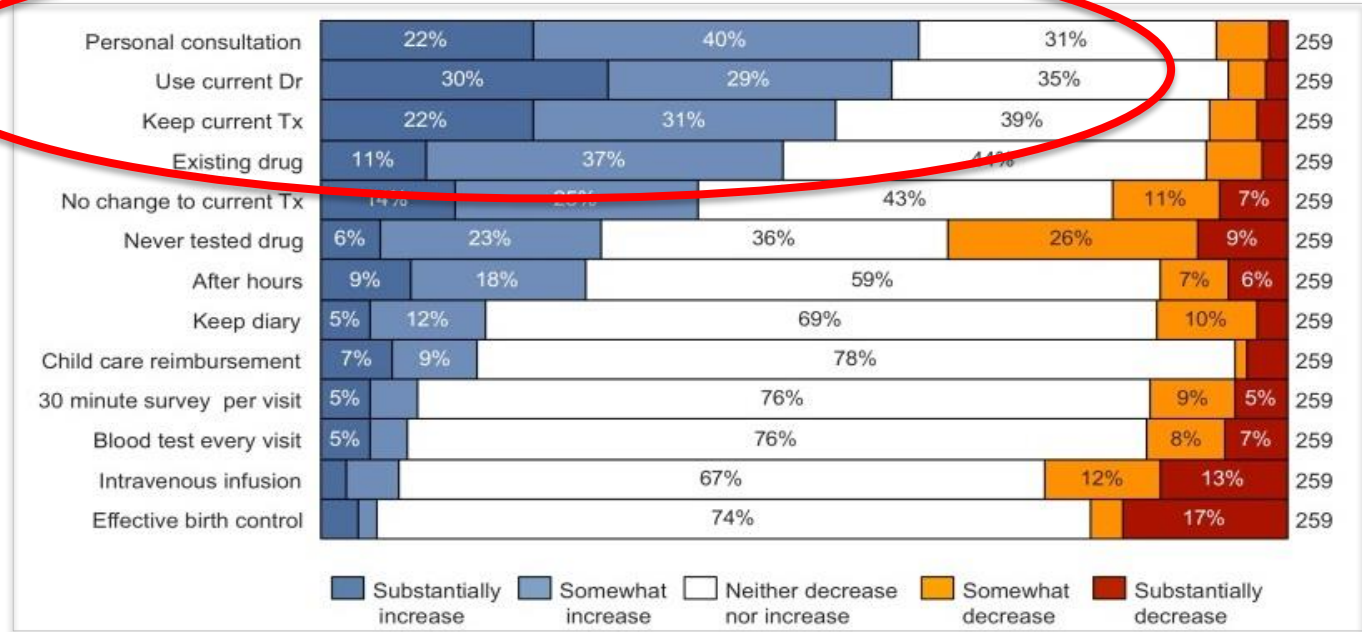


Lupus / Digital Patient Communities

Key Insights

- ❖ Insights into disease and treatment experience insights
- ❖ Uncovered structural factors that hinder trial enrollment
- ❖ Revealed protocol-specific facilitators and barriers to recruitment and retention

Would these factors increase or decrease the likelihood of participation?



ARMD / Trial Simulatie



Atrofisch-leeftijd gerelateerd macula degeneratie / phase II trial



USA consumenten panel, uitgevoerd in market research omgeving



Doelstellingen: beter begrijpen impact van aandoening, belasting tgv typische trial visite, knelpunten in protocol design, opties om deelnemers betere ervaring te geven



ARMD/ Trial Simulation

Value & impact



Transportation

Centralized transportation and hotel
Escort door to door service



Lengthy Study Procedures

Implemented a split visit schedule
Ensure site has comfortable waiting area



Electronic Informed Consent

Larger monitors installed
Paper copy with large print



Study Treatment and Surgery

Included animation video in ICF
Ongoing discussion regarding retreatment of sham patients

Tevredenheids bevraging via internet survey

THANK YOU!

Thank you for taking part in this study!

We'd like to learn more about your experience, so we've created a short survey for you to take. Your feedback will help researchers design more effective, patient-friendly, and successful research studies in the future.

Your opinion matters. Completing this survey is voluntary and your name will not be used.

Please scan the QR code to the right or visit the link below in the next 10 days to share your perspective.

HealthiVibe.com/HealthiPerspectives/201501/US



Your study site ID number is: _____. You will need this number to participate in the survey.



How satisfied were you with your overall clinical research study experience?

1 - Not at all
satisfied

2 -Slightly
satisfied

3 -Moderately
satisfied

4 - Very
satisfied

5 - Completely
satisfied



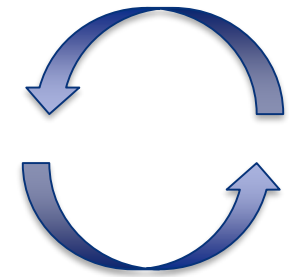
Prev

Next

10%



Dankuwel!



PATIENT

TOEGANG

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janssen

PHARMACEUTICAL COMPANIES

OF *Johnson & Johnson*

