



Projectresultaten in vogelvlucht/ *real world-data*

Een consortium opzetten van A tot Z?

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OPTI-CLOT/ To WiN studiegroep & SYMPHONY NWO-NWA consortium

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Disclosures: Marjon Cnossen

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Employee	No relevant conflicts of interest to declare
Consultant or Major Stockholder	No relevant conflicts of interest to declare
Speakers Bureau or Honoraria	No relevant conflicts of interest to declare
Scientific Advisory Board	Steering board member: Roche, Bayer and Novartis.

Mattheus Passion



MATTHÄUS PASSION IN CIJFERS *symphographic*



2 orkesten



koren



jongenskoor



solisten

2

delen met 68 stukken

14

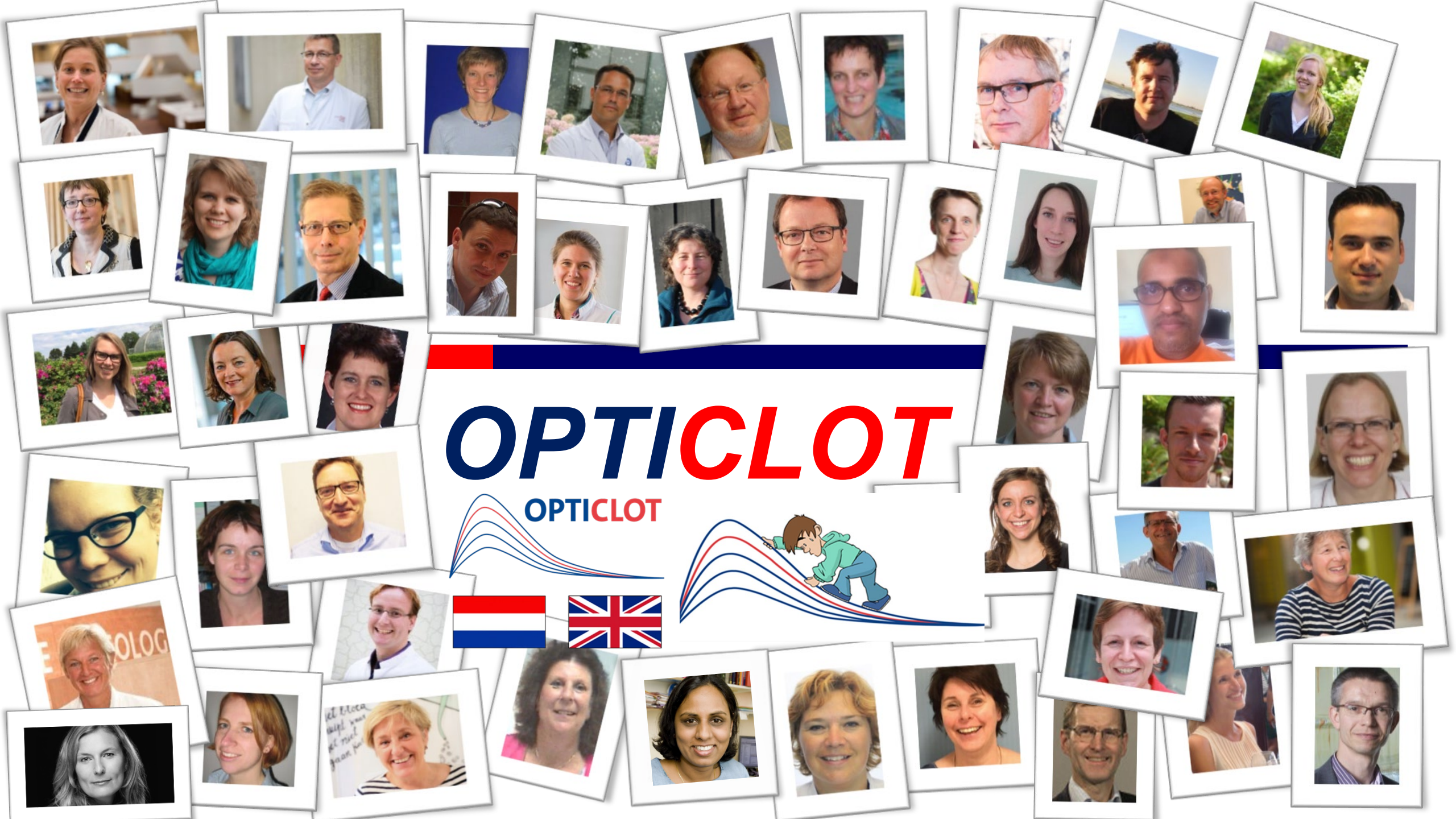
koralen

27

aria's en koorgedeeltes

Bekendste aria:
Erbarme dich

Première op
Goede Vrijdag 11 april 1727



OPTICLOT

OPTICLOT



The background features several overlapping circles in a light purple color. A solid dark blue horizontal band runs across the middle of the image, containing the text 'SYMPHONY CONSORTIUM' in white, bold, uppercase letters.

SYMPHONY CONSORTIUM

Scientific team

- 14 fte PhD -> 17 PhDs
- 1 post doc 3 jaar
- Materiele kosten & andere posten



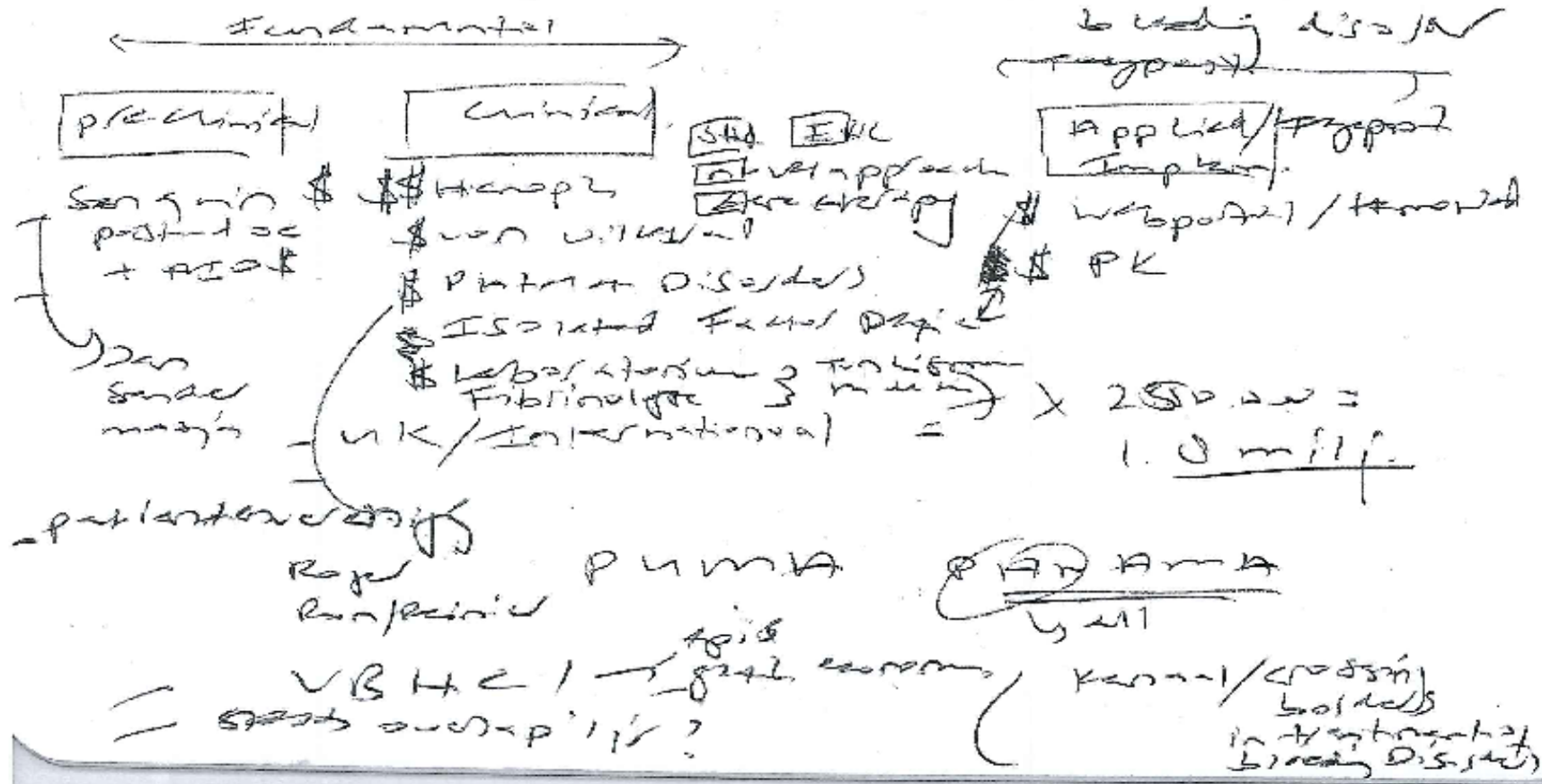
Onderdelen/ Fasen

1. Concept/ idee
2. *Repeteren*: Incubatieperiode & schrijven
3. *Uitvoering*: De dagelijkse praktijk
4. *Geluid & licht*: Tips & tricks
5. 😊

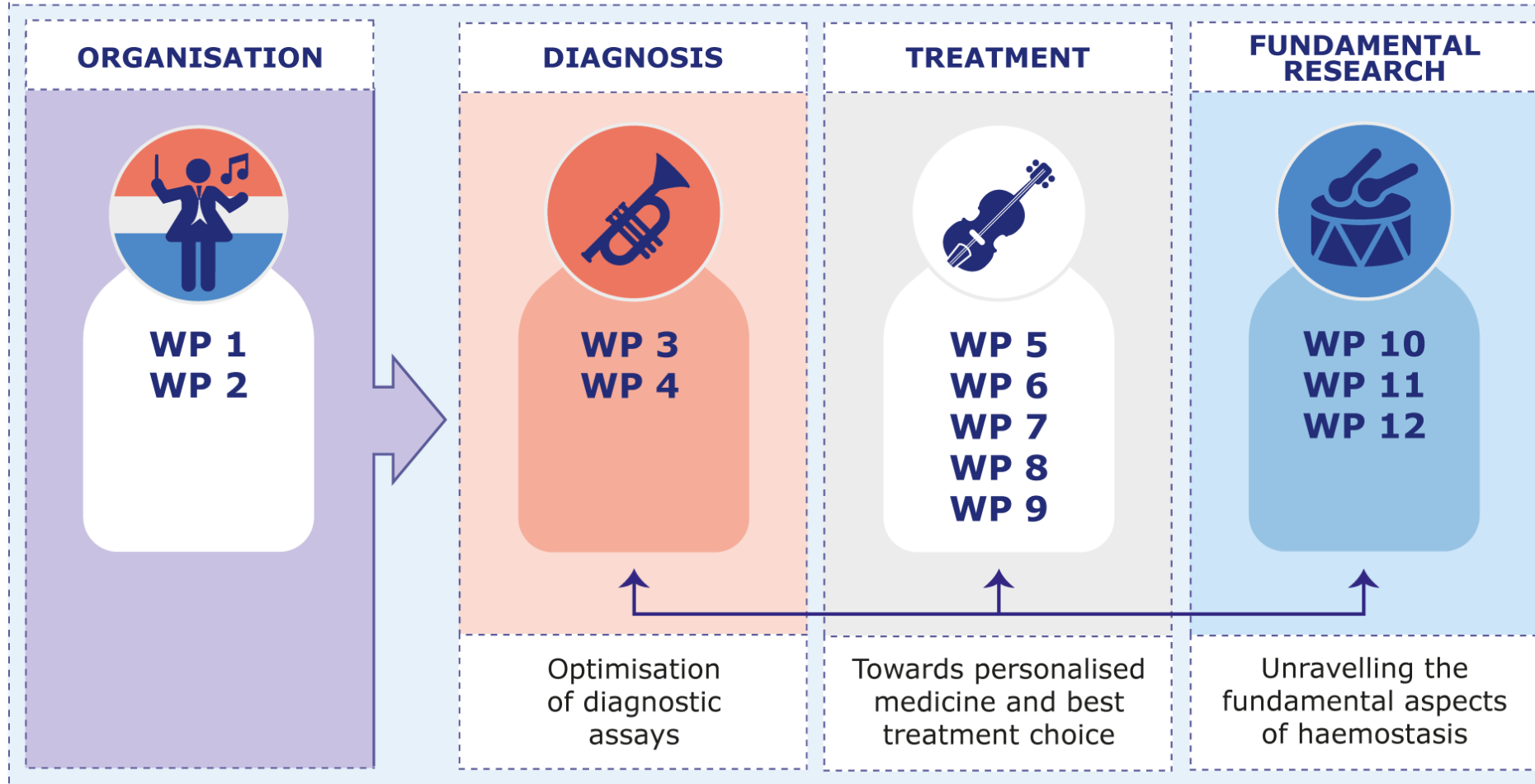
The background features several overlapping circles in a light purple color. A solid dark blue horizontal bar spans the width of the image, positioned in the middle. The text 'CONCEPT/ IDEE' is written in white, bold, sans-serif capital letters on this bar.

CONCEPT/ IDEE

Personalized Medicine
for individuals with a
breeding disorder



PERSONALISED TREATMENT FOR PATIENTS WITH A BLEEDING DISORDER



Workpackages

ORGANISATION

WP 1: Management

WP 2: Knowledge utilisation and/or entrepreneurship

THEME 1 Optimisation of diagnostic assays

WP 3: Novel diagnostic assays for coagulation factor deficiencies

WP 4: Advanced diagnostics for platelet function disorders

THEME 2 Towards personalised medicine and best treatment choice

WP 5: Establishing a value-based health care approach

WP 6: Dose individualization of factor concentrates and desmopressin using population pharmacokinetic (PK) modeling

WP 7: Implementation of novel treatment strategies by e-health systems

WP 8: Costs and effects of personalised treatment in bleeding disorder patients

WP 9: Ethical dilemmas of treatment choice

THEME 3 Unravelling the fundamental aspects of haemostasis

WP 10: Linking the proteome to bleeding phenotype

WP 11: Unravelling the genetic origins of platelet disorders using iPSC model systems

WP 12: The endothelial compartment as disease modifier in bleeding disorders

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REPETEREN

Incubatieperiode & schrijven

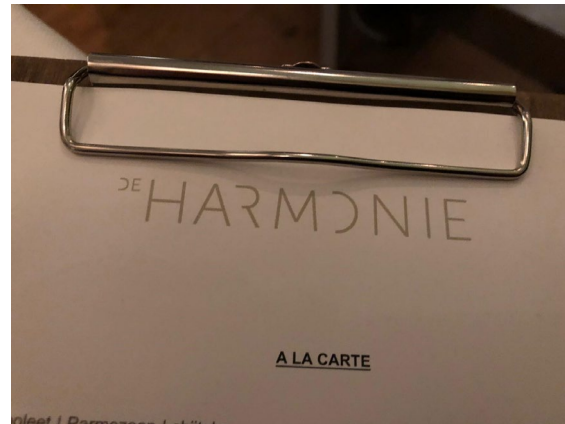
1. Mindset/ Tijd maken
2. *Call*: goed lezen, luisteren
3. Structuur/ organisatie alle onderdelen subsidieaanvraag (Trello)
4. *Partner in crime*/ hulp (junior-, taken verdelen)
5. Overige partners oplijnen: *Research & development office*, financiële controller, data-management, TTO, ervaringsdeskundigen
6. Communicatie!
7. Regelmatig overleg consortium in spé
8. Onderhandelen

"*Last en zeker niet least*"

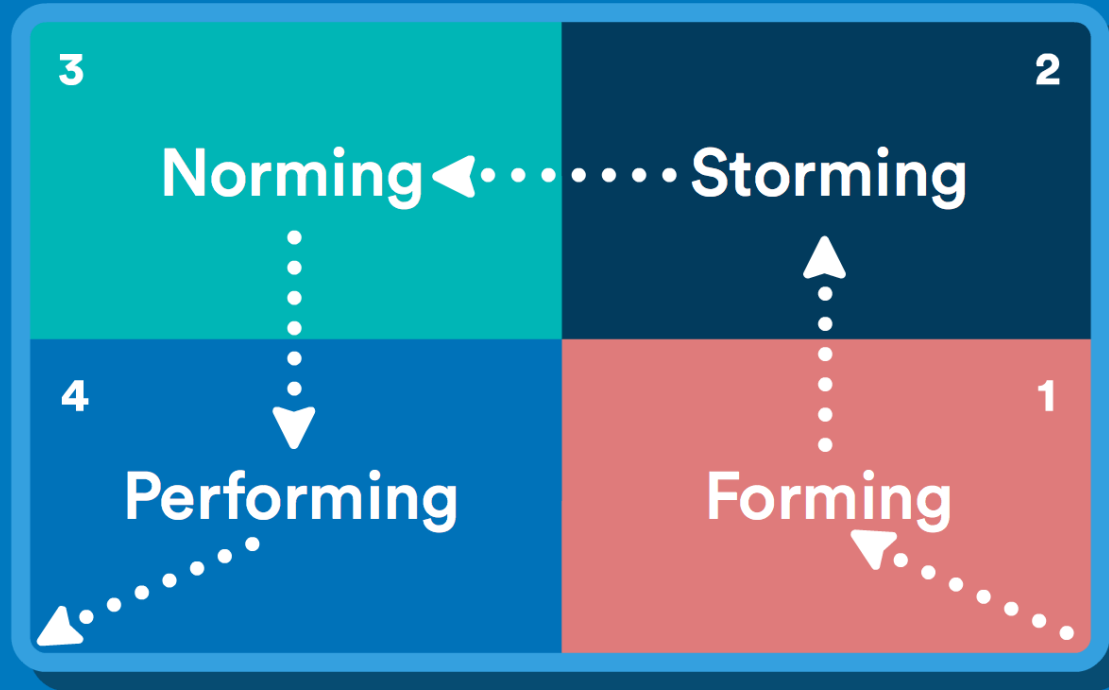


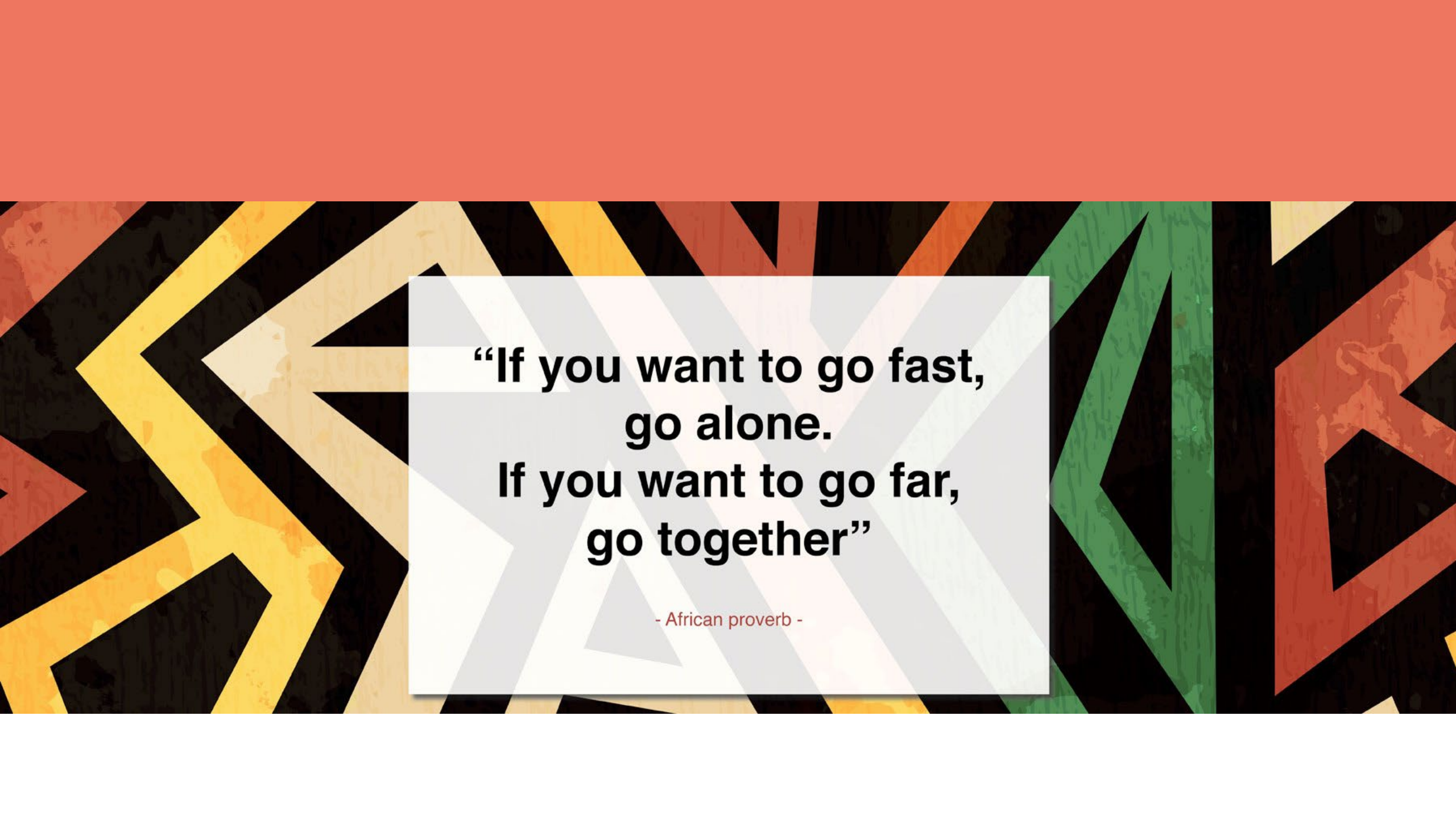
Incubatieperiode & schrijven

9. Plezier maken: genieten van het proces



Incubatieperiode & schrijven





**“If you want to go fast,
go alone.
If you want to go far,
go together”**

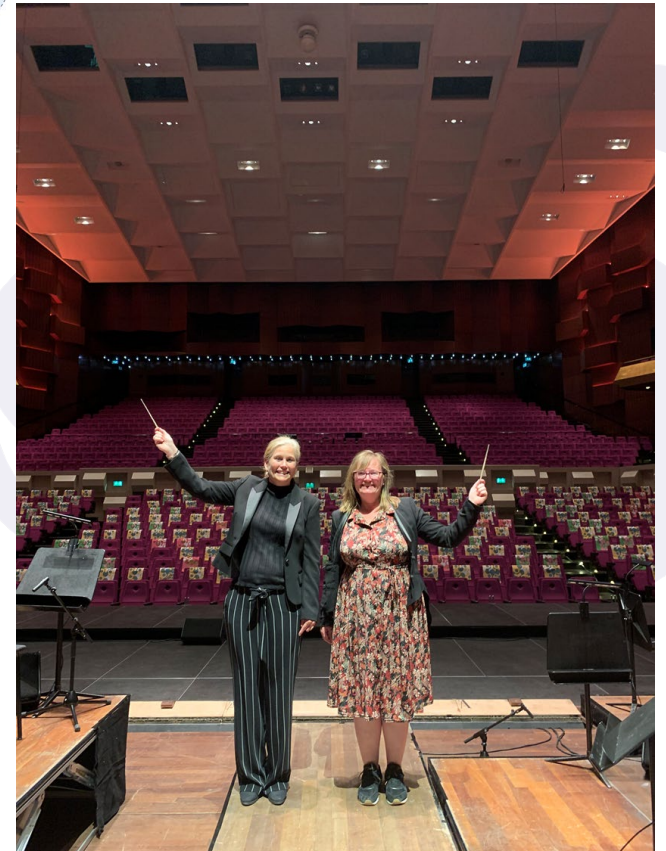
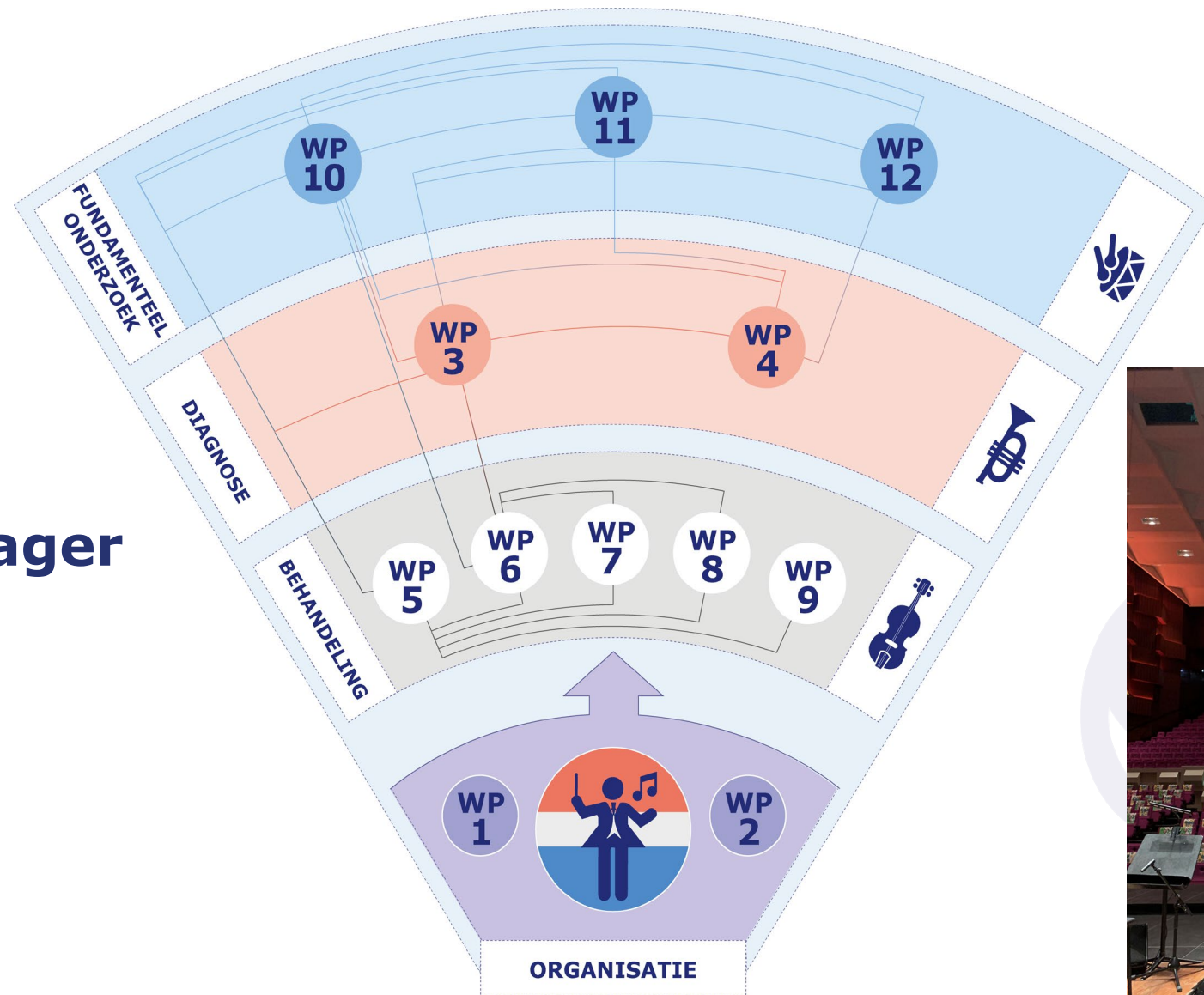
- African proverb -

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UITVOERING



Project manager



De dagelijkse praktijk

Organisatie

1. Vergaderschemas/ ruimtes (management, plenair, WP leaders)
2. Investeren in project manager!
3. Governance uitvoeren
4. Impactplan/ voortgangsverslagen
5. Aanvullende financieën & onderhandelen
6. Branding van het consortium
7. Output bewaken registeren & bewaken
8. Social media
9. Stakeholders betrekken/ betrokken houden
- 10. Plan-do-check-act**



The background features several overlapping circles in a light purple color. A solid dark blue horizontal band runs across the middle of the image, containing the text 'GELUID & LICHT' in white, bold, sans-serif capital letters.

GELUID & LICHT

Tip & Tricks

Administratie

1. Maandelijkse meeting WP leaders (*Quick-notes*)
2. Bonding (COVID 2020): Theme meetings naast General Assembly
3. PhD happiness: PhD commissie, PhD day
4. SYMPHONY on tour

Recent Accomplishments:

List all accomplishments from last month

- Successful meetings
- Successful experiments
- Achieved milestones & deliverables

All Output&Milestones → CPA:

- Which milestones are achieved?
(make sure they are also in the CPA on SharePoint)
- Output: posters, articles, talks, all information you shared (make sure to upload on SharePoint!)

Spin off:

- (Most) PhDs are funded by SYMPHONY all sideprojects are therefore spin off
- New opportunities/projects are spin off

Actions	Timeline	Responsible
What will be done coming month(s)	When should this be done?	Who is responsible/involved This can be someone from another workpackage!
Made sure you update this every month!		

Milestones (🎵 = achieved): (M=0 on 16-09-2019)

- Here the milestones & deliverables of SYMPHONY are set by WP. Check the dates (especially if a red block is added) to explain delay (block "Opportunities/Issues") or make sure accomplished milestones are in "All Output&Milestones" and at the CPA portal: [CPA submissions](#)
- In case of delay strike through deadline and write down new deadline

Opportunities / Issues:

- Describe issues that may cause a delay or cancellation in the project (which milestone?)
- Describe new opportunities, new collaborations, new initiatives, etc

Tip & Tricks

Administratie

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😊 Trots op wat je doet met elkaar/ identiteit: (grapjes, gadgets)

😊 Mens-gericht zijn, met elkaar optrekken (congressen)

Team science & Citizen science



SYMPHONY PHDS & POST-DOC



biochemists - fundamental scientists - statisticians - value based health care specialists - health care cost analysts - geneticists



clinical pharmacologists - psychologist - ICT experts - medical specialists - laboratory specialists - epidemiologists - ethicists



patient society - (cel)biologists - philosophers - medical technology assessment specialists - pharmaceutical companies



Young talent in the multicenter SYMPHONY consortium lead by Dr Marjon H. Crossen (PI) and Dr Simone Reitsma (PM)

Persoonlijke noot



“Jouw persoonlijke noot
maakt voor onze patiënten
het verschil”

Key to personalize treatment in rare diseases in general





Nederlandse Vereniging voor Trombose en Hemostase



umcg



UMC Utrecht



máxima
medisch centrum





Questions & Suggestions

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