VII Jornada EN Cáncer DE Mama Hereditario

Telegenetics & Mainstreaming
the UMCG experience

Rolf Sijmons

*Dept Genetics, **U**niversity **M**edical **C**enter **G**roningen, the Netherlands*

Organizado por:

GEICAM investigación en cáncer de mama
www.geicam.org

SOLTI INNOVATIVE BREAST CANCER RESEARCH
www.gruposolti.org

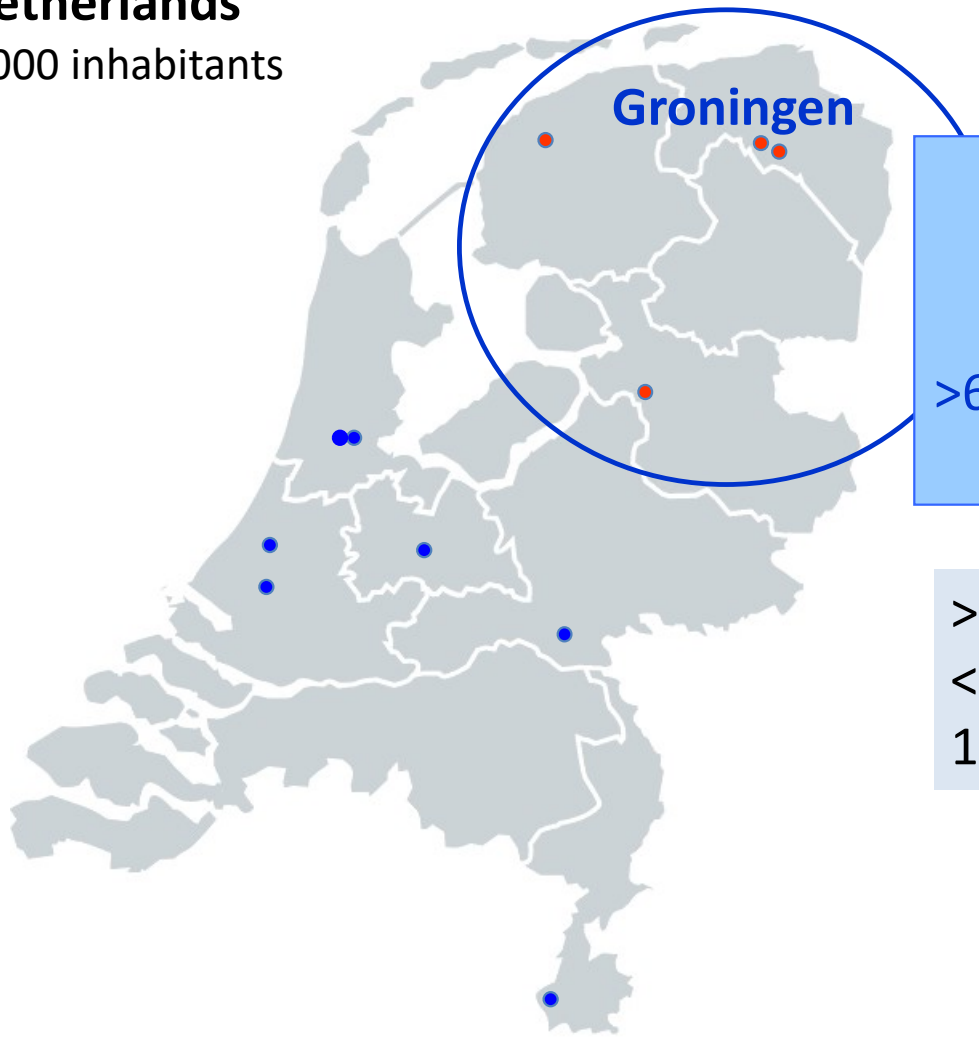
Sección SEOM Cáncer Familiar y Hereditario
www.seom.org

Disclosure Information

- Employment: University Medical Center Groningen
- Consultant or Advisory Role: -
- Stock Ownership: -
- Research Funding: Dutch Cancer Society, UMCG/DASH
- Speaking: -
- Grant support: -
- Other: -

The Netherlands

~ 17,400,000 inhabitants



~2.2 million
in our service area

>6700 referrals annualy

>1/3 Familial Cancer
<1/3 Cardiogenetics
1/3 Rest

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University Medical Center Groningen

Telegenetics in the UMCG
2004- today

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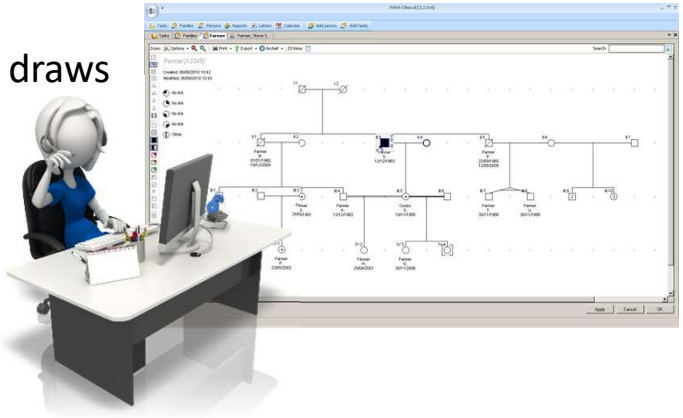
Traditional sequence of counseling & testing events

referral

Patient receives and
fills out family history form

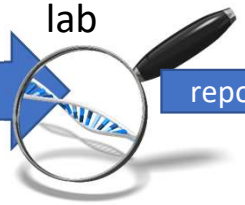
Secretary draws
pedigree



Intake at Genetics clinic

DNA testing

Genetics
lab



In case of abnormal result
2nd appointment at clinic

report

Final report

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Our historical view on different appointment types

PROS

known

CONS

1. **Limitation of number of rooms**
2. **Need to create ‘blocks’ of appointments**
3. **Patient needs to travel (time, money)**
4. **Doctor needs to travel**
5. **Hospital environment stressful**

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PROS

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1. **Easy to schedule**
2. **No need for patient to travel**
3. **No need for doctor to travel to clinics at regional hospitals**
4. **Patients might be more at ease in their own home**
5. **No technical issues (phone)**

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1. **Cannot see patient & doctor**
2. **Patient may still need to travel to a *local* clinic for bloodsampling**
3. **No physical examination possible**

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As for phone PLUS

1. **Can see patient & doctor**
2. **Share screens**

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or smartphone

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1. **PC, webcam, (headset) needed**
2. **Possibly technical issues (PC, camera, sound, internet speed)**
3. **Computer skills needed**

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Telemedicine uptake among Genetics Professionals in Europe

*Otten, E et al. Eur J of Hum Genet **2015***

- Survey completed by n= 104 clinically active European genetics professionals (including 10 from 8 locations in Spain)

- **17% used telephone genetic counseling**
- **9% used video genetic counseling**

P.S. in several fields of clinical genetics physical examination is a must

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Telegenetics use in presymptomatic genetic counselling: patient evaluations

*Otten, E et al. Eur J of Hum Genet **2015***

n= 57 patients who were presymptomatic cardiogenetic (n=17), presymptomatic oncogenetic (n=34), and prenatal (3 couples)

1/3 consented to video counseling (and had the equipment needed)

Technical problems occurred in almost 50% of online sessions.

Nonetheless patients were overall satisfied with video counseling

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Online genetic counseling from the providers' perspective

Otten, E et al. Eur J of Hum Genet 2016

- Pilot study of 51 home-based online counseling sessions for cardiogenetic and oncogenetic pre-symptomatic testing, and urgent prenatal counseling
- Counselors reported frequent technical problems.
- **Counselors were unsatisfied with video counseling**

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Pre-COVID-19 (2019) session types in our dept

- **<10% video counseling** (also true for oncogenetics)
- >90% physical appointments at our outpatient clinics

P.S. when working at the Genetics dept Open Office: reservations for dedicated video-rooms were a severe limitation

BACKGROUND (2019 data, source: Dutch Central Bureau of Statistics)

- **97% of Dutch population has access to internet**
- 88% of Dutch population uses the internet every day

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During COVID-19 pandemic (2020, 2021)

60% **video counseling (97% for oncogenetics**, >2000 sessions/yr) WEBEX©

40% physical clinical appointments

Almost all clinical geneticists / counselors work, at least part-time, from their home office

BACKGROUND (source: GfK – 'Trends in Digital Media' 2021)

- 75% of Dutch population uses videochats
- 40% uses videochats more frequently than pre-COVID
- >50% of population aged 65 years and older uses videochats

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Are we satisfied we telegenetics (video)?

- YES: Patients + doctors
- Even though there are still technical issues in 5-10% : need to switch to phone call

(keep in mind that last year's alternative would have been: no sessions at all)

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Plans post-Covid

- No going back to in-hospital oncogenetic counseling as major type
- Most geneticists plan to keep working from their home office for part of the week for video counseling
- We consider closing all out-patient oncogenetics clinics in regional hospitals
- We will switch to Dutch Zaurus© platform as of June 1st 2021, it is cheaper and will be integrated with our EPIC© EHR

Mainstreaming of genetic testing for hereditary cancer

primary goal or involving secondary findings

Focus on cancer patients rather than on healthy relatives

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Tumor-first (somatic and germline findings)

- All ovarian cancer (2018-..) because of choice of therapy
  - NGS BRCA 1 / 2 testing (soon to be expanded) by Molecular Pathology lab
  - Referral to Genetics when BRCA1 /2 pathogenic variants are observed

- Leukemia (2019 - ..) because of classification/prognosis/therapy
  - NGS panel run by Laboratory Medicine dept. All cases discussed in tumor board
  - **variant >40% allele frequency** in gene also known to be involved in hereditary leukemia **AND** persisting after remission
    -> referral to Genetics dept

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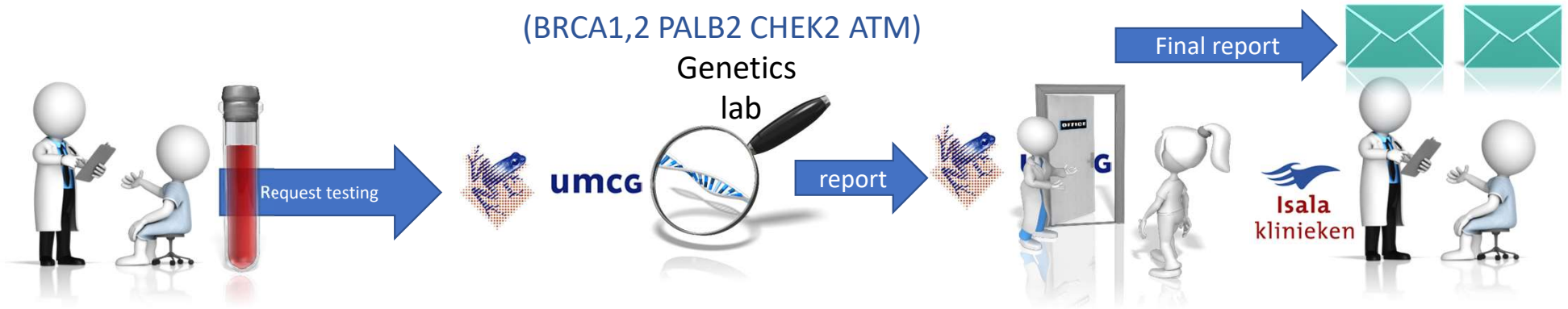
Fast track hereditary breast cancer testing (2 weeks)



Started in 2018

All regional hospitals that provide breast cancer care participate

Participants generally satisfied

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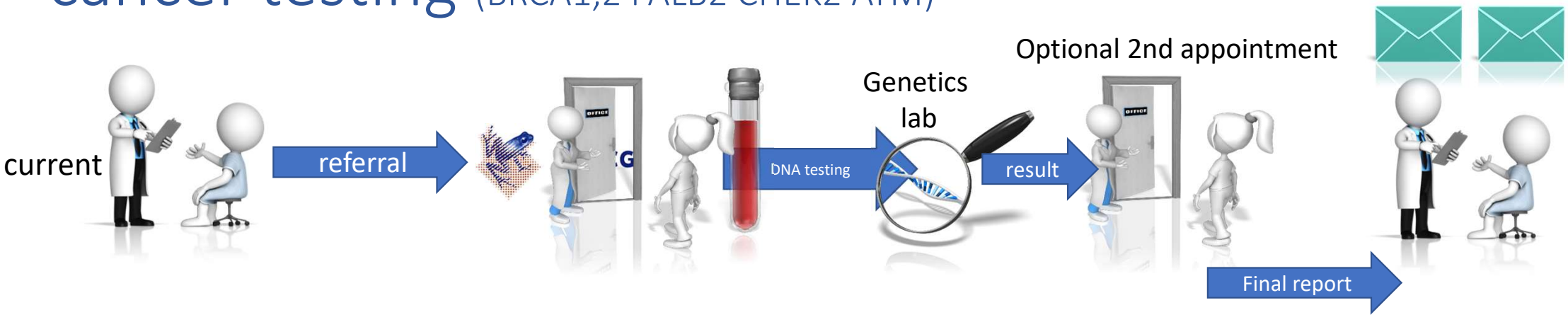
Starting 2021: mainstreaming of hereditary breast cancer testing (BRCA1,2 PALB2 CHEK2 ATM)



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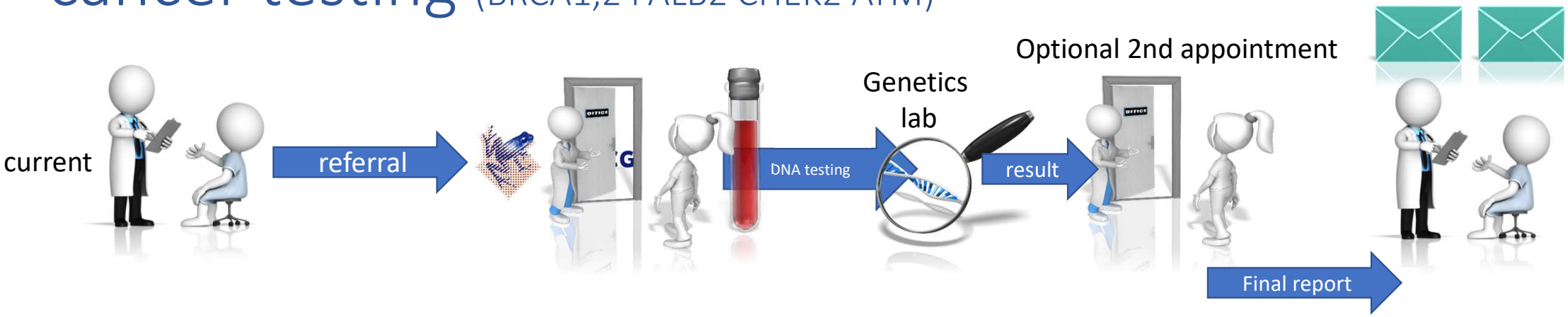

Why mainstreaming?

- Make care path easier for patients (no additional hospital & doctors)
- Make care path faster (no additional referral, no waiting list)
- Mainstreaming results in more volume at Genetics dept for those complex cases

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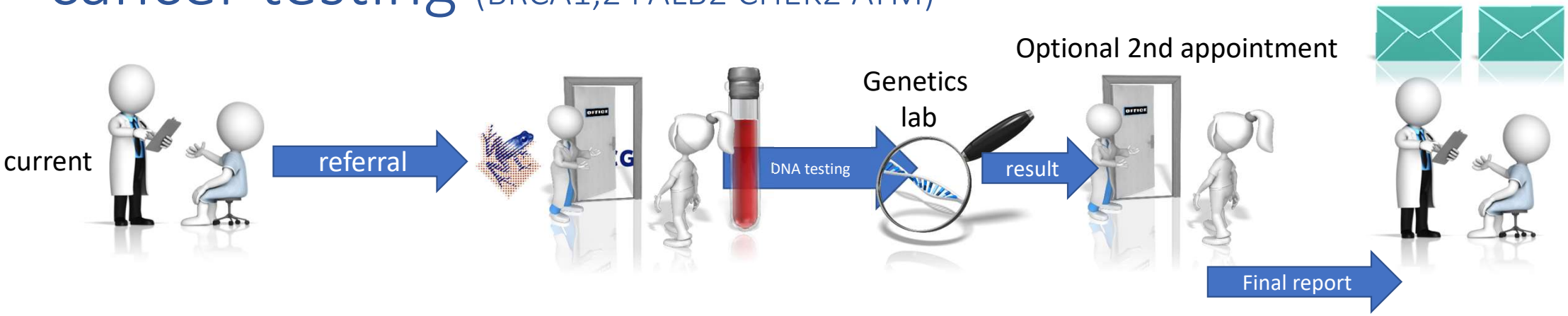

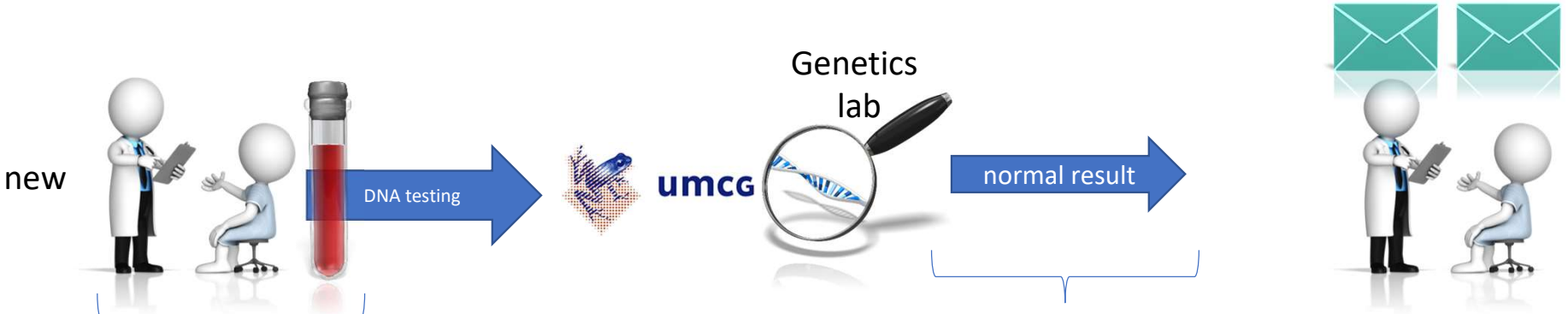

For **selected cases** (decision tree)

In case of **abnormal result** or other reason for further exploration of family: an appointment at Genetics clinic is scheduled

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Educational program for this care path

- Follow e-learning module
- Session with hands-on training in using procedure / forms using virtual patients (organized by Genetics dept)
- Use the decison-tree for selecting patients
- printed information for counseling available

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Barriers

Education
Geneticists: fear of losing quality control / fear of change

How much extra time will this cost me?

Will I get paid ‘doing the geneticists job’?

Will we loose income/jobs as genetics department?

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General observations

Based on our experience (the Netherlands):

- Telegenetics using online video platforms is now embraced by patients as well as professionals
- Technical issues exist in minority of sessions but are no major barrier to customer satisfaction

- Mainstreaming is not a primary goal: it is a tool to improve health care
- Mainstreaming of genetic testing is rapidly increasing:
  - Through tumor diagnostics (ovarian cancer, others)
  - Germline testing for breast cancer and other cancers
- Bariers to mainstreaming:
  - Education, time, money, fear of change