



UNIVERSITÄTS
KLINIKUM FREIBURG



GRAILS

Eigenproduktion – die bessere Alternative?

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ESID CD4 def-subregistry

USER ID: 105
Login: test.benjamin

PATIENT ID:
12320

Menu:

- Core Dataset:**
- General, Diagnosis, QoL
- Ig-replacement & Antibiotics
- Other treatment & Adverse Events
- Laboratory values
- Concomitant diseases
- Infections
- Additional modules:**
- Family history
- Extended Laboratory
- Percentiles


Core data: General
Visit Date: 2010-01-19 ✖

Patient Info

Patient ID 12320 ?	Patient consent Full consent ?	Familial case --- ?	
Date of birth 1999 - - ?	Sex Male ?	if yes: Family Number	?
Date of death - - ?	Country of residence Netherlands ?	Consanguinity --- ?	
Attending centre (Austria) --- ?	Current status alive ?	Twin --- ?	
Attending centre (NL) --- ?	Reported to REDIP? --Please select-- ?	REDIP ID	?
	Country of birth --- ?		

Diagnosis

Genetic mutation --- ?

only genetically diagnosed ? unknown ?
 unknown ?

Date of first clinical diagnosis of PID - - - ?
 Date of genetic diagnosis - - - ?

Reason for genetic analysis ?
 Analysis following clinical diagnosis Family screening Prenatal diagnosis
 Diagnosis by neonatal screening unknown

Sequencing method ?
 Gene sequencing Whole exome/genome sequencing unknown

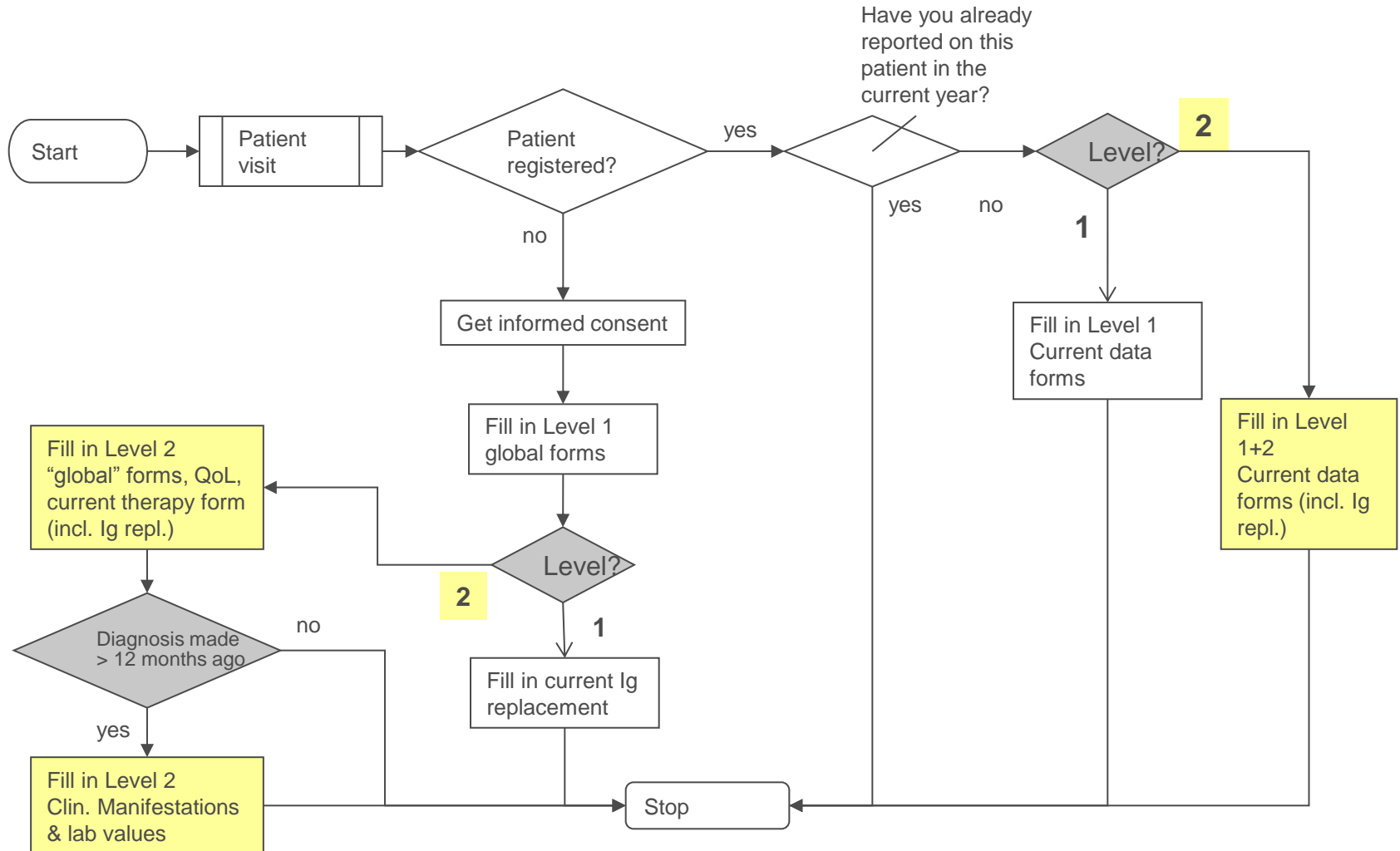
Onset of symptoms suggestive of PID - - - (date YYYY-MM-DD)
 Or approximate age in years: -please select - ? unknown

First symptom suggestive of PID: ?
 Infection Immune dysregulation ? Malignancy
 Syndromal manifestations ? Other, specify:
 unknown no symptoms

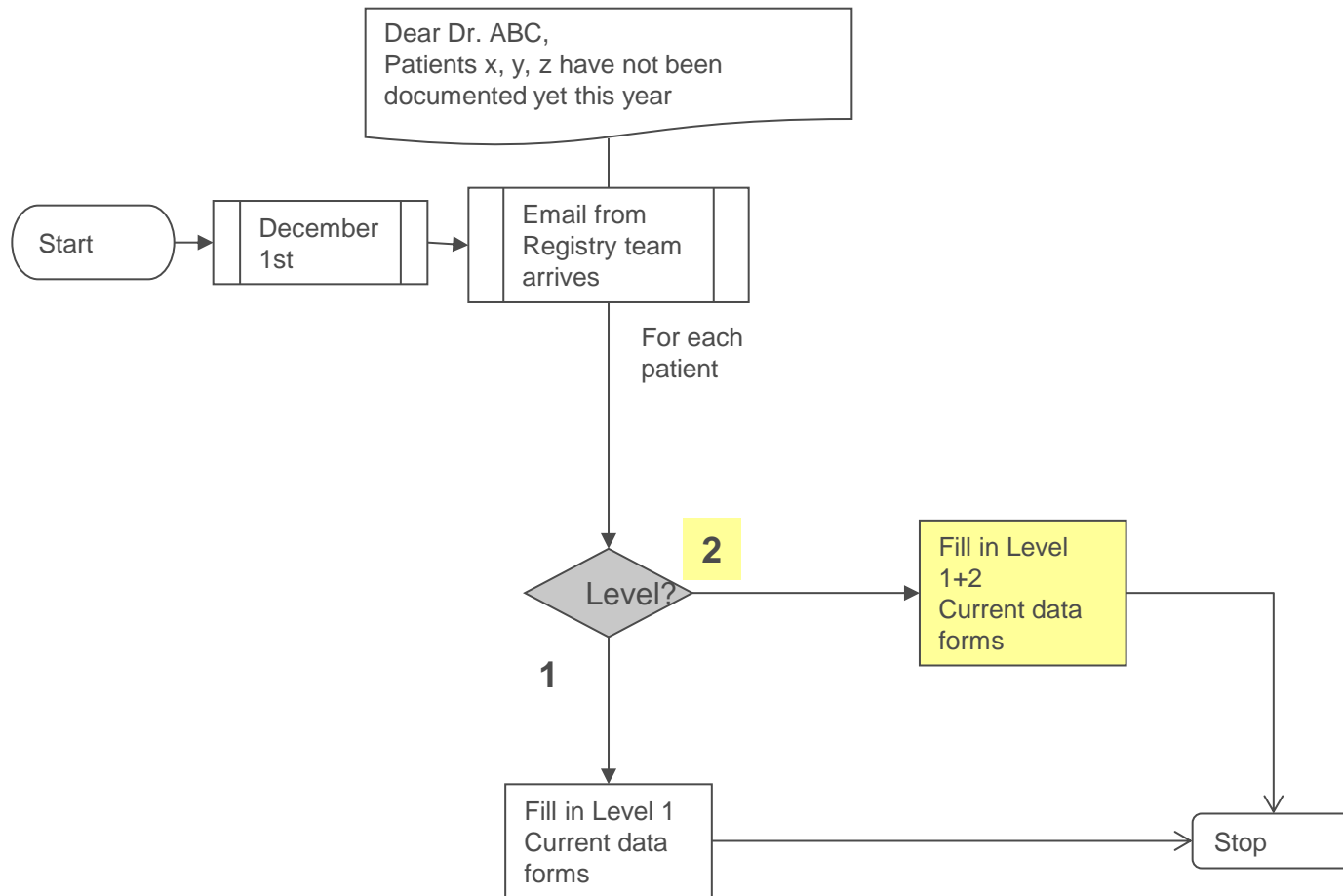
Altes Register / alte Software

- Unvollständige und inkonsistente Daten
 - Aufteilung der Variablen in „Level“ 1,2,3
 - Forciertes Einsetzen von Validitätsprüfungen
 - Benutzerführung
 - Erinnerungsmails

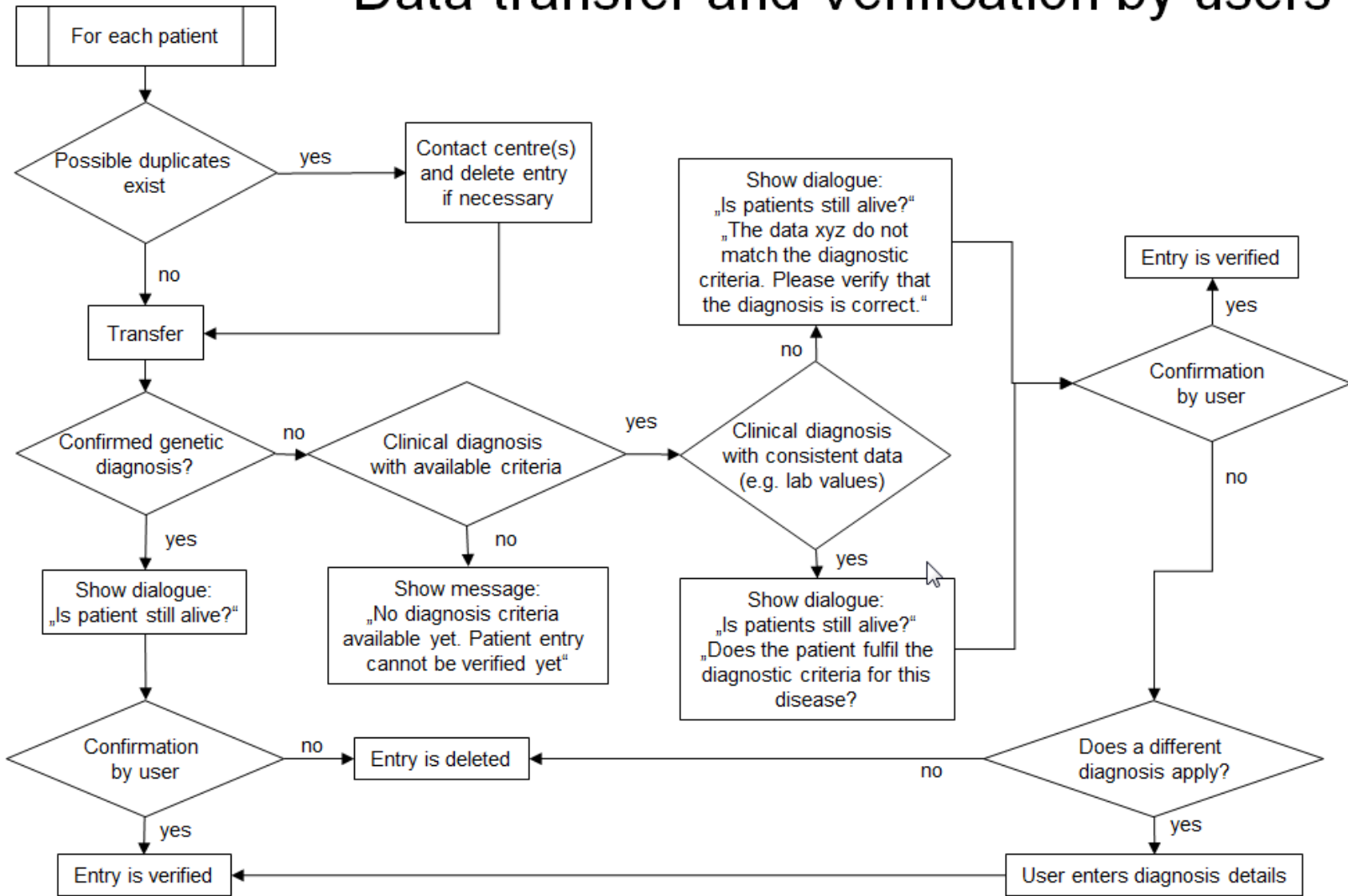
Patient visit



Annual reminder



Data transfer and verification by users





Auswahl einer Software



- Review verschiedener Frameworks
- Auswahl von Grails („Groovy on Rails“)
- Framework auf JVM, in Groovy geschrieben, baut auf Spring, Hibernate und SiteMesh auf
 - Sehr flexibel
 - Sehr aktive Benutzer-Gemeinschaft
 - Vielfältige Plugins
- Auch andere Lösungen wären denkbar gewesen!

Patient view

 = form not completed
 = Form complete

ESID ID: 35 - Year of birth: 1995 - Age: 18 / Documentation date: 2013-11-08

Patient ✓ | Way to Diagnosis ⓘ | PID Diagnosis ⓘ | Current Status ✓ | Ig-Replacement ⓘ | HSCT ⓘ | Gene therapy ⓘ

Edit Patient

ESID ID	?	35
Patient Consent	?	<input checked="" type="radio"/> Full consent <input type="radio"/> Research only <input type="radio"/> Not applicable
Date of birth	?	Year: 1995 Month: <input type="text"/>
Sex	?	<input type="radio"/> Male <input checked="" type="radio"/> Female <input type="radio"/> Unknown
Country of Birth	?	Australia
Country of Residence	?	Germany
Familial Case	?	<input type="radio"/> Yes <input type="radio"/> No <input checked="" type="radio"/> Unknown
Consanguinity	?	<input type="radio"/> Yes <input type="radio"/> Probable <input type="radio"/> No <input checked="" type="radio"/> Unknown
Twin	?	<input type="radio"/> Yes: identical <input type="radio"/> Yes: non-identical <input type="radio"/> Yes, but heredity unknown <input type="radio"/> No <input checked="" type="radio"/> Unknown
Documenting Centre		Freiburg 1, Immunology

Save Reset

Verification process

Confirm clinical criteria

Please select

The clinical criteria for **Autoimmune lymphoproliferative syndrome (ALPS)** are:

Splenomegaly (palpable or ultrasound)
OR Lymphadenopathy (>3 nodes, >3 months, non-infectious, non-malignant)
OR Autoimmune cytopenia (>/= 2 lineages)
OR History of lymphoma
AND
TCRab+CD3+CD4-CD8- of CD3+ T cells >6%
OR
elevated biomarkers (at least 2 of the following):
*sFASL > 200pg/ml
*B12 > 1500ng/L
*IL-10 > 20pg/ml
note: validated for pre-treatment values, all laboratory criteria may change significantly upon treatment

Does the patient fulfil the diagnostic criteria for this disease?

Yes No Unknown

OK **Cancel registration process**

If there is no genetic diagnosis, you are asked to confirm the clinical criteria.

Überlegungen

- „Fertige“ Register-Software:
 - Formular-Editoren genügen nicht
 - Ablauf-Logik lässt sich schwer in einer GUI bearbeiten → Arbeit am Quellcode erforderlich
- Transfer von Altdaten als häufige Herausforderung
- Anbindung von anderen Systemen, z.B. Mainzelliste
- Häufigstes Problem: Spezifikation zu Beginn nur in Ansätzen vorhanden, vielfältige Änderungen im Programmierprozess



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Stephan Rusch
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Bodo Grimbacher
Stephan Ehl



Grails im Internet: <http://grails.org/>

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