ERN-RND | 13.12.2018 | Tübingen For questions and support please mail at: sanja.hermanns@med.uni-tuebingen.de



European Reference Network

for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

USER GUIDE CLINICAL PATIENT MANAGEMENT SYSTEM





CPMS User Guide Summary



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I CENTRE DASHBOARD

- 1. Panels
- 2. Patient list
- 3. Enroll patient
- 3a. Consent Forms
- 4. Consultation Form
- 4a. Consultation Request

4b. Patient Information

Annex - additional/optional sections
in the consultation form:
4c.Episode Description
4d. Rare Disease Diagnosis
4e. Comorbidities
4f. Phenotype/Genetic Features and
Biobanks
4g. Family History
4h. Special Treatment Intervention
4i. Transplantation History
4j. Medication History
4k. Medical Documents

- 5. Panel Workflow
- Panel Selection
- Data Completion
- Assessment
- Outcome
- Sign-Off
- Close and/or Archive
- 6. Timeline
- 7. Meetings
- 7a. Schedule Meeting
- Invite participants
- 7b. Join a meeting
- 7c. Finishing meetings
- Meeting summary

II ERN DASHBOARD

- 1. Panels
- 2. Task list
- 3. My meetings
- 4. Preferences





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- 3
- General: Use as a web-browser Google Chrome, it is recommended to have a minimum dedicated 350kb/s down per download stream as well as 350kb/s up per uploaded stream to maintain a stable video connection.
- You can fill out the consultation form in several returns if you save the sections you have already filled
- You can decide which sections are most useful to describe the case in your particular situation, some of them are marked HERE ,Optional' but maybe for your particular case essential. You can use them.
- There are date pickers '\u00ed where you have to fill the date in the format dd/mm/yyyy, but some date pickers allow to write only mm/yyyy, or yyyy
- If you're not sure about the exact requirement of a box check the' ⁽¹⁾ icon for more information





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- □ Login into CPMS: <u>https://cpms.ern-net.eu/login/</u>
- D 2 main applications/dashboards: 'Centre' and 'ERN'

European Reference Networks		Centre ERN Map 🤉 🕶 📤 Dr.
Applications	Training Videos	CPMS user manual and documentation
🛱 Centre	Introduction to CPMS	🙂 User Manual
× ERN	Of CPMS Webinar- General introduction	Aulti level role-based access
🖽 Мар	OCPMS Webinar- How to use the Consultation Form	Coding systems & Data standards
	CPMS Webinar- How to form an Expert Panel	Be-Identification in CPMS
	CPMS Webinar- How to schedule video meetings	Kan Image Viewer
	OF CPMS Webinar - how to use the Medical Viewer	Data Hosting
	CPMS Webinar- Users Access rights	🛃 Patient Consent Sample
	OCPMS Webinar- Non-ERN Health Professionals	🖺 Outcome Document Template
	CPMS Webinar - ERN Coordinators	Good Practices of the Informed Consent
		Toolkit and Case Study for Health professionals





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- □ You can see all panels of your institution
- □ You can enroll a new patient
- You can view the current patients of the centre
- □ Search patients by their nickname, first or last name, CPMS ID, panel ID

*Remember: All authorized users from this centre can see all patients enrolled within this centre regardless of enrolling user.

European Reference Networks	ERN DE22 - Tübi	ingen University Hos				Centre ERN	Map 🛛 🗸 👗 Dr.	
	🛱 DE22 - Tübing	gen University Hospit	al USER: Dr.	4.				
23 Dashboard	Patients		1	Search	2	Recent Activity		2
Enrol Patient	& Enrol F	Patient	4	First name, last name, CPMS ID, panel ID or nickname	Search	CPMS Id	Date	
않 Patient List	≇ Patier	nt List	4					
Panels	2.							





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□ See all panels of your institution

ropean eference etworks	ERN [0E22 - Tübingen University	Hos		Ce	ntre ERN M	lap 🛛 🗸 🛔 rndhpuser5 testuser -			
Ē	BDE22 - Tübingen University Hospital USER: rndhpuser5 testuser									
4	📽 Patient Panels									
F	Panel ID 🕇	Nickname	Started *	Lead	State 🔭	ERN	Thematic Area			
#	# 150	gdgbd	19/Sep/2017	Holm Graessner	Open	ERN-RND - Neur	Atypical parkinsonian syndromes: Ge			
#	# 600	Test Data Migration2	14/Jun/2018	doctor 2	Data Co	ERN-EYE - Eye D	Neuro Ophthalmology rare diseases			
#	# 666	leaf	31/Jul/2018	rndhpuser5 testuser	Panel Sel	ERN-RND - Neur	Cerebellar Ataxias and Spastic Parapl			
#	# 725	yellow	14/Sep/2018	rndhpuser5 testuser	Panel Sel	ERN-RND - Neur	Cerebellar Ataxias and Spastic Parapl			
#	# 215	Smitthers	23/Oct/2017	Doctor Two	Panel Sel	ERN-EYE - Eye D	Neuro Ophthalmology rare diseases			
#	# 731	Another	19/Sep/2018		Open	ERN-EYE - Eye D	Neuro Ophthalmology rare diseases			
#	# 206	Nick	19/Oct/2017	Doctor One	Data Co	ERN-EYE - Eye D	Neuro Ophthalmology rare diseases			
#	# 358	ZAC	08/Jan/2018	doctor 4	Open	ERN-EYE - Eye D	Neuro Ophthalmology rare diseases			
#	# 208	Ben	19/Oct/2017	Doctor Two	Panel Sel	ITHACA - Intelle	Syndromic cardiac disorders			
#	# 2	EYE_TestPatient1	16/Jun/2017	hany mina	Aborted	ERN-EYE - Eye D	Retina Rare Eye Diseases			
#	# 41	test 1	20/Jul/2017	Helene Dollfus	Panel Sel	ERN-EYE - Eye D	Retina Rare Eye Diseases			
#	# 37	sf	20/Jul/2017	hany mina	Open	ERN-EYE - Eye D	Anterior Segment Rare Eye Diseases			
#	# 19	Demo Patient	03/Jul/2017	hany mina	Data Co	ERN-EYE - Eye D	Pediatric Ophthalmology Rare Diseases			
#	# 14	Bill	26/Jun/2017	hany mina	Panel Sel	ERN-EYE - Eye D	Pediatric Ophthalmology Rare Diseases			
#	# 18	Demo patient	03/Jul/2017	hany mina	Data Co	ERN-EYE - Eye D	Pediatric Ophthalmology Rare Diseases			
#	# 36	sd	19/Jul/2017	hany mina	Open	ERN-EYE - Eye D	Anterior Segment Rare Eye Diseases			





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🕈 Enrol Patient

See all enrolled patients of your centre



DE22 - Tübingen University Hospital USER: rndhpuser5 testuser

📽 Patient List

Last Name	First Name	Record Label	CPMS Id	Enroled	Gender •	Date Of Birth	=
Eye	Oeil	Eye, Oeil DOB: 03/04/2000 (m	ERN-de22-002	16/Jun/2017	М	03/Apr/2000	^
One	Patien	One, Patien DOB: 02/06/2017	ERN-de22-003	01/Jun/2017	F	02/Jun/2017	
Test	Test	Test, Test DOB: 08/02/1962 (ERN-de22-004	20/Jun/2017	Μ	08/Feb/1962	
Test	Demo	Test, Demo DOB: 09/08/2013	ERN-de22-005	02/Jul/2017	Μ	09/Aug/2013	
Demo	Demo	Demo, Demo DOB: 07/01/20	ERN-de22-006	03/Jul/2017	UN	07/Jan/2016	
х	Mr	X, Mr DOB: 03/07/2017 (unde	ERN-de22-007	28/Jun/2017	UN	03/Jul/2017	
Test	Bert	Test, Bert DOB: 08/01/1983 (ERN-de22-009	20/Jul/2017	M	08/Jan/1983	Е
Testman	Fred	Testman, Fred DOB: 03/05/19	ERN-de22-010	24/Jul/2017	M	03/May/1969	
TestPerson	Freddy	TestPerson, Freddy DOB: 07/	ERN-de22-012	26/Jul/2017	M	07/May/1993	
TestLady	Jenny	TestLady, Jenny DOB: 29/02/1	ERN-de22-013	26/Jul/2017	F	29/Feb/1984	





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Required fields are in red; the patient must give consent for care

Enrol Patient				
Patient Id: EI	RN-de22-005			
* Date enrolled:	dd/Mmm/yyyy			
Pre-qualification check				
* Have you sought advice on this patient at a national healthcare provider @ organisation?	Yes 💿 No			1
			t n	ownload Model Concent Forms
Consents				
Consent Requested	Consent Given	Date		
Consent for care	🔘 Yes 🔘 No			
Consent for ERN databases/Registries	🔘 Yes 🔘 No			
Consent contact for research				
Identifying data				
* First name				
* Last name				
* Gender:	•			
* Date of birth:	dd/Mmm/yyyy			
* Record Label				0







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□ Available in 25 different languages

Download Consent Forms

Download Consent Forms (pdf format)

- BG (20/11/2017)
- CS (04/05/2018)
- DA (20/11/2017)
- DE (05/03/2018)
- EL (20/11/2017)
- EN (20/11/2017)
- ES (04/05/2018)
- ET (20/11/2017)
- FI (20/11/2017)
- FR (04/05/2018)
- GA (20/11/2017)
- HR (20/11/2017)

- HU (20/11/2017)
 IT (04/05/2018)
- LT (20/11/2017)
- LV (21/11/2017)
- MT (20/11/2017)
- NL (20/04/2018)
- NO (05/12/2017)
- PL (04/05/2018)
- PT (20/11/2017)
- RO (20/11/2017)
 SK (20/11/2017)
- SL (20/11/2017)
- SE (20/11/2017)
 SE (20/11/2017)

Reference

Guidelines Toolkit Case Study

Good Practices Informed Consent Data Management

-	_	_	_			
L	O	n	s	e	n	TS 1
-	-		-	-		

Consent Requested	Consent Given	Date	
Consent for care 1. This consent is mandatory	● Yes ◎ No X	23/May/2018	
Consent for ERN databases/Registries 2 . This consent is not mandatory, thus the answer can be'No'. If 'Yes' it authorizes Panel leads to make the clinical data available for ERN researchers after panels have been closed and an outco The Name and Date of Birth will still not be visible for them.	Yes No X me has been signed-off.	23/May/2018	Please specify Here you can just write 'OK'
 Consent contact for research 3. This consent is not mandatory, thus the answer can be'No'. If 'Yes' it states patients are interested to be contacted by outside ERN research projects (e.g., e.g.) 	Yes No X that clinical trials)	23/May/2018	Please specify Here you can just write 'OK'





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- Heart of the case discussion (consultation process), necessary to reach a consensus for diagnosis and treatment
- Composed of multiple sections; you can decide which of them and how detailed you will fill
- Can be edited in the 'Edit' view
- Several coding systems available (e.g. ICD, ICCC-3/10, HPO, ORDO, LOINC etc.), pick one or more of them
- □ Search widget: type first letter of a phenotype to get suggestions



Consultation form – 4a. Consultation Request



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	•	Arrient ID: ERN-de22-030	Beispiels, Testa DOB: 24	/03/2004 (F) Enrolled: 3	31/Jul/2018					
	Panels	출 # New Panel								
		I New Consultation Form								
	Enrolment	Consultation Request								
	7	Consolitation Request								
		Episode Description			Do not use any	nicknames liable to identity the patient, including his/her first name or last name.				
		Rare Disease Diagnosis								
Different sections	s of the	Comorbidities			* Nickname	leaf				
consultation form	n, only the	Phenotype/Genetic Features and Biobanks		Is urgency requi	ired for this nanel?					
	, only the	Family History		is digency requi	red for this parter.					
sections 'Consulta	ation	Health Behaviours	* Is this a repeat o	f a previous panel for the s	same patient but a	🔘 Yes 💿 No 🔘 Don't know				
Request' and 'Pa	tient	Allergies and Other Adverse Reactions			different episode?					
nformation' are i	mandatory	History of Past Illness and Disorders		* Consultation Request	Description Short:	Unclear diagnosis				
	,	Special Treatment Intervention		* Consultation	- Description					
		Surgical Procedures		 Consultation 	n Request Reason:	Ulagnosis Treatment Other				
		Transplantation History		* Consultation Request Re	eason Description:	Contradictory indications: WES vs. phenotype				
		Medication Summary				#				
		Others Medical Documents		* He	ealthcare Provider:	DE22 - Tübingen University Hospital				
		The status		taut tour	t of same specialists	In these settings Panel Lead - Po	int of Care Specialist			
		i ne nickna	ame of the pa	tient	t of care specialist:	manpusers testuser III threse settings I and Ecad - I c	and of care opecialise			
		will be visi	ble for panel		* ERN:	© ERN-EYE				
						ERN-RND ERN-RND				
		members	external to yo	ur		ITHACA				
		contro: it i	c one of the			RARE-LIVER				
		centre, it i	s one of the		* Panel Lead:	rndhpuser5 testuser				
		searchable	e items in CPN	/IS *P	rimary Thematic Area:	 Atypical parkinsonian syndromes: Genetic PD, Multisystem Atrophy, Progressive Supranuclear Palsy, Corticobasal degeneration 				
						 Cerebellar Ataxias and Spastic Paraplegias 				
						Choreas and Huntington's Disease				
						 Dystonias, paroxysmal disorders (nonepileptical ones) and Neurodegeneration with Brain Iron Accumulation 				
						 Frontotemporal dementia 				
						C Leukodystrophies				
				Seco	ndary Thematic Areas					
				5220		Atypical parkinsonian syndromes: Genetic PD, Multisystem Atrophy, Progressive Supranuclear Palsy, Corticobasal degeneration				
						Choreas and Huntington's Disease				
						 Dystonias, paroxysmal disorders (nonepileptical ones) and Neurodegeneration with Brain Iron Accumulation 				

Frontotemporal dementia
Leukodystrophies

_ . .

Save the consultation form every time you fill new section cancel save



Consultation form-*4b. Patient Information*

A Patient ID: ERN-de22-030 Beispiels, Testa DOB: 24/03/2004 (F) Enrolled: 31/Jul/2018



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Panels	
-	

Enrolment

🐮 # New Panel

■ New Consultation Form	Patient Information		
Consultation Request	+ Add birth complication		
Episode Description	* Gender:	Female	
Rare Disease Diagnosis		O Male	
Comorbidities		O Undifferentiated	
Phenotype/Genetic Features and Biobanks		O Unknown	
Family History	Δ Pregnancy:	🔿 Yes 🖲 No	
Health Behaviours			
Allergies and Other Adverse Reactions	* Country of Residence (ISO 3166-1):	Germany	
History of Past Illness and Disorders	Country of birth (ISO 3166-1):	Germany	
Special Treatment Intervention	Education Level (ISCED 2011):	ISCED 1: Primary education	
Surgical Procedures			
Transplantation History	Occupation:	Pupil, student, further training, unpaid work experience	
Medication Summary			
C Others	 Add functional status and/or disability 		
Medical Documents			

Cancel Save After filling the minimum mandatory

'Patient Information', you will be led to the 'Panel Workflow' site





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□ Has 8 stages, to be kept on track *via* the tracker







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- Open new panel: after enrolling new patient or from the patients' list for a previously enrolled patient
- □ Form the panel by inviting other Health Professionals to join.
- Remember: they should have chosen the same thematic area as you (s. page ERN 'Preferences') in order to appear in your list as possible invitees.







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You can invite members to your panel from your thematic area, from other thematic areas or from whole ERN.

Panel Selection

Available	Invited	Co-ordinator Assistance				
Thematic Area:	Cerebellar	Ataxias and Spastic Paraplegia	5		-	
Available Healthcare Professionals Role Role						
rnd coordinator					surgeon	Invite
rnd database					surgeon	Invite
rndhpuser4 test	tuser				surgeon	Invite

Accept the panel invitation on behalf of the invited panel members in the tab 'Invited', otherwise they will be automatically set to ,refused' when you proceed to the step Data Completion.

Available Invited Co-ordinator Assistance		
nvited Panel Members		
Name	Role	Status
rndhpuser5 testuser		Lead
rnd database	surgeon	Invited -
rndhpuser4 testuser	surgeon	Accept
rnd coordinator	surgeon	Set As Lead

ransition	to	Data	Completion	

Panel		
Name	Status	
rndhpuser5 testuser	Lead	
rnd database	Invited	
rndhpuser4 testuser	Invited	
rnd coordinator	Invited	
rndhpuser1 testuser	Invited	
rndhpuser3 testuser	Invited	
rndhpuser2 testuser	Invited	

You have invited Panel Members who have not responded. If you continue, their invitations will automatically be marked as Refused.





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- As a panel lead you can accept or refuse the invitation for the others on behalf of your self, or set another panel member to be a panel lead.
- □ Setting panel lead:

Panel Selection

- Use case 1: the panel lead is from the originating /enrolling centre of the patient, ALL users from this centre can edit the consultation form and transition the workflow.

- Use case 2: the panel lead is from another centre but within the same ERN, ONLY panel members from the enrolling centre and the panel lead can edit the consultation form, the panel lead can transition the workflow and sign-off the outcome.

Role	Status	When	Panel Member	s Status Actions
Role	Status	When	Member	Status Actions
			rndhpuser5	Lead Invited:
	Lead	Invited: 13/Sep/2018	rndhpuser1 testuser	Invited Invited: 13/Sep/2018
surgeon	Invited -	Invited: 13/Sep/2018	rndhpuser3 testuser	Invited Invited: 13/Sep/2018
Radiologist	Accept	Invited: 13/Sep/2018	rndhpuser2 testuser 3 invitations ar	Invited Invited: 13/Sep/2018 re outstanding
Surgeon	Set As Lead	Invited: 13/Sep/2018		Э
	14		rndhpuser5 rndhpuser1 he panel	testuser 13/Sep/2018 1 testuser was invited to jo
			rndhpuser5 rndhpuser3 he panel	testuser 13/Sep/2018 1 testuser was invited to jo
			rndhpuser5 rndhpuser2 he panel	testuser 13/Sep/2018 1 testuser was invited to jo
	Radiologist Surgeon	Radiologist Accept Surgeon Set As Lead	Radiologist Accept Refuse Set As Lead Invited: 13/Sep/2018	Radiologist Accept Refuse Set As Lead Invited: 13/Sep/2018 Close Close Close Close Add a common comparison com



5. Panel Workflow – Data Completion



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□ After the panel selection proceed to the next step in the workflow





5. Panel Workflow – Data Completion



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□ At this stage you can provide more information on the patient *via* the 'Edit' button

European Reference Networks	ERN DE22 - Tübingen University Hos	Cent	tre 🛛 ERN Map 💿 👻 🍐 rndhpuser5 testuser 🗸
•	A Patient ID: ERN-de22-030 Beispiels, Testa DOB: 24/03/20	4 (F) Enrolled: 31/Jul/2018	
Panels	활 #666 leaf	« Prev Open Panel Data Selection Completion	Assessment Outcome Sign-off Closed
=) Inrolment	Centre DE22 - Tübingen University Hospital Lead rndhpuser5 testuser Panel rndhpuser3 testuser (Surgeon) rndhpuser3 testuser (Radiologist) rndhpuser2 testuser (Surgeon)	ERN Thematic Area	ERN-RND - Neurological Diseases Cerebellar Ataxias and Spastic Paraplegias
	A Please complete the Patient File for this Panel.	۲	Schedule Meeting
	CONSULTATION RECORDED: 31/JUL/2018 14:55 (EUROPE/BERLIN) B FORM EDITED: 12/OCT/2018 15:05 (EUROPE/BERLIN) BY:	RNDHPUSER5 TESTUSER	© TIMELINE *

Now you can choose among these sections the ones that should be filled out and

hest describe the nationt.	Consultation Request
best describe the patient.	Patient Information
	Episode Description
	Rare Disease Diagnosis
4	Comorbidities
A	Phenotype/Genetic Features and Biobanks
	Family History
	Health Behaviours
	Allergies and Other Adverse Reactions
•	History of Past Illness and Disorders
	Special Treatment Intervention
	Surgical Procedures
	Transplantation History
	Medication Summary
	Others
	Medical Documents





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×

After 'Data Completion' proceed to the next step 'Assessment'

Transition to Assessment

20

You have chosen to transition to a new state, Assessment.







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 In this step, panel members can make contributions to the case via the 'Record Contribution', they can view the other panel members' contributions by clicking on their tab, or 'Request Additional Data'

嘧 #666 le	af	« Prev Image: Complexing complexing Image: Complexing complexing Next > Open Salerting Complexing Complexing Complexing Closed
	Centre DE22 - Tübingen University Hospital Lead rndhpuser5 testuser Panel rndhpuser1 testuser (surgeon) rndhpuser3 testuser (Radiologist) rndhpuser2 testuser (Surgeon)	ERN ERN-RND - Neurological Diseases Thematic Area Cerebellar Ataxias and Spastic Paraplegias
nel Contributions	rndhpuser1 testuser rndhpuser3 testuser rndhpuser2 testuser	Additional request text
		Close





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- □ The panel has to consider and decide an outcome
- Save Panel Outcome the Panel Lead records the outcome and the other panel members can view, comment on or edit it.
- □ At this stage the outcome remains a draft, the panel cannot be closed

	Transition to Outcome	×
	You have chosen to transition to a new state, Outcome .	
	Cancel Continue to Outcom	e
Panel Outcome (draft)		×
Write the Panel Outcome:		⊙ Timeline 🗼
		Outcome (draft)
		An outcome has not been produced.
		0,0 🗸 🗸
		Add a comment
	Cancel Save Panel Outcome (draft)	





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□ When the outcome is complete, the Panel Lead can sign it off, s. also next page

Outcome (draft) Panel Outcome Lorem ipsum dolor sit amet, consetetur sadipscing elitr, sed diam nonumy eirmod tempor invidunt ut labore et dolore magna aliquyam erat, sed diam voluptua. At vero eos et accusam et justo duo dolores et ea rebum. Stet clita kasd gubergren, no sea takimata Outcome: Lorem ipsum dolor sit amet, consetetur sadipscing elitr, sed diam nonumy eirmod tempor invidunt ut labore et Sanctus est Lorem ipsum dolor sit amet. Lorem ipsum dolor sit amet, consetetur sadipscing elitr, sed diam nonumy eirmod tempor invidunt ut labore et dolore magna aliquyam erat, sed diam dolore magna aliquyam erat, sed diam voluptua. At vero voluptua. At vero eos et accusam et justo duo dolores et ea rebum. Stet clita kasd gubergren, no sea takimata sanctus est Lorem ipsum eos et accusam et justo duo dolores et ea rebum. Stet dolor sit amet. clita kasd gubergren, no sea takimata sanctus est Lorem 13/Sep/2018 ipsum dolor sit amet. Lorem ipsum dolor sit amet, 2 • • consetetur sadipscing elitr, sed diam nonumy eirmod tempor invidunt ut labore et dolore magna aliquyam rndhpuser5 testuser 13/Sep/2018 14:46 rndhpuser5 testuser updated Outcome erat, sed diam voluptua. At vero eos et accusam et justo duo dolores et ea rebum. Stet clita kasd gubergren, no rndhpuser5 testuser 13/Sep/2018 14:52 sea takimata sanctus est Lorem ipsum dolor sit amet. rndhpuser5 testuser updated Outcome Cancel Save Panel Outcome Sign-off Panel Outcom

The Outcome will not be editable once it is Signed Off. Do you want to continue?

Cancel OK





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- □ The Panel Lead confirms the outcome, and signs it off
- □ The panel can then be closed, at that stage the outcome can no longer be edited
- All panel members can export the outcome as pdf document for personal record or the Panel Lead can send it over to the Point-of-Care specialist or the patient

European Reference Networks	ERN DE22 - Tübin	ngen University Hos		Centre ERN Map 🛛 🗕 🛔 mdhpuser5 testuser 🗸
•	& Patient ID: ERN-d	e22-030 Beispiels, Testa DOB: 24/03	2004 (F) Enrolled: 31/Jul/2018	
Panels	🖀 #666 leaf		Open Panel Da Selection Comp	ta Assessment Outcome Sign-off Closed
➡ Enrolment	Centre Lead Panel	DE22 - Tübingen University Hospital rndhpuser5 testuser rndhpuser1 testuser (surgeon) rndhpuser3 testuser (Radiologist) rndhpuser2 testuser (Surgeon)	Thematic	ERN ERN-RND - Neurological Diseases Area Cerebellar Ataxias and Spastic Paraplegias
		Comparison of the second	ERN-de22-031 ERN-RND - Neurological Deseases DE22 : DE22 - Tübingen University Hospital Deseases DE22 : DE22 - Tübingen University Hospital University Hospital diam nonumy elimod tempor invidunt ut tevero ese et accusam et justo taximata sancture et Lorem Isum dobr et wolpita. At vero ese et accusam et justo	PDF-Datei exportieren Adobe Export PDF PDF-Datein in Word oder Excel Online Konvertieren DFD-Datei auswahlen 2272disf-5379-410e14cia0c/?8a.pdfX Konvertieren nach Microsoft Word (*.doc) Dokumentsprache: Deutsch Andern Konvertieren





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The outcome document is available for all panel members







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□ The panel lead has the option to make the panel available for research.







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 If the panel has been archived, it can only be viewed from the 'Centre' application by members of the centre where the patient was enrolled and not from the 'ERN' application.







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O Timeline ∻ Panel Members 2 Member Status Actions rndhpuser5 testuser Lead Invited: 13/Sep/2018 rndhpuser1 testuser Accepted Invited: 13/Sep/2018 Accepted: 13/Sep/2018 rndhpuser3 testuser Accepted Invited: 13/Sep/2018 Accepted: 13/Sep/2018 rndhpuser2 testuser Accepted Invited: 13/Sep/2018 Accepted: 13/Sep/2018 There are no outstanding invitations 6 **9** 🗸 13/Sep/2018 14:12 rndhpuser5 testuser rndhpuser1 testuser was invited to join the panel rndhpuser5 testuser 13/Sep/2018 14:12 rndhpuser3 testuser was invited to join the panel rndhpuser5 testuser 13/Sep/2018 14:13 rndhpuser2 testuser was invited to join the panel rndhpuser5 testuser 13/Sep/2018 14:18 rndhpuser5 testuser accepted on behalf of rndhpuser1 testuser rndhpuser5 testuser 13/Sep/2018 14-18 rndhpuser5 testuser accepted on behalf of rndhpuser3 testuser rndhpuser5 testuser 13/Sep/2018 14:18 rndhpuser5 testuser accepted on behalf of rndhpuser2 testuser Add a comment Meeting: Case discussion Description Invited: rnd coordinator (Invited), rnd database (Invited), rndhpuser1 testuser (Invited), rndhpuser2 testuser (Invited), rndhpuser3 testuser (Invited), rndhpuser4 testuser (Invited), rndhpuserS testuser (Host) Scheduled: 11/oct/2018 14:53 (Europe/Berlin) for 15 minutes o loin Meeting Test 0 🗩 🗸 Add a comment

- Shows near real-time transition of the panel based on the actions triggered by a Panel member or Lead
- It is a chatting tool AND allows panel members to make comments on images, contributions and outcome documents
- It can be seen by all panel members
- Contains the 'Join Meeting' button





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- 2 options: individual meeting or part of a recurring meeting (the host must select an available time slot for that meeting)
- The Host can invite other Health Professionals to join the meeting including those who are not part of the panel.
- **The meeting can be divided into time slots if discussing multiple patients**





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Close 🛛 👾 Schedule Meeting

- When scheduling a meeting you can choose between an ERN recurring meeting or an individual meeting
- You can invite participants via the tab 'Participants' and write meeting 'Summary' as a preparation for the meeting and conclusions after the meeting
 Meeting: Case discussion

e & Time	Participants	Summary					Test video Starts in: 3 day(s) Meeting commen
		Title of meetin Descriptio	g: Case discussi	on				Add a comment
		Meeting Statu	s: Upcoming				•	
		Whe	n: 17/sep/2018 17/Sep/2018 0	1 0:30 (Europe/Berlin) 8:30 (UTC)				
		Duratio	n: 30 minutes					
	Schedule meeti	ng						>
			Title of meeting: Description:	Case discussion				
			Type of meeting	 Part of ERN recurring meeting Individual meeting 				
			When:	17/Sep/2018		10:30	Europe/Berlin	
			Duration:	30	minutes			



7a. Schedule Meeting – Invite participants



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- Invite proposed participants or search for participants via the 'Invite' field
- □ The invitee receives a notification of the invitation, he/she must first accept or decline it via ERN-Dashboard → 'My Meetings', 'Member Task list' or 'Panel' (s.ERN-Dashboard)

Meeting: Case discussion			5
Date & Time Participants Summary	Τε	est video Starts in: 3 day(s)	Meeting comments
Name	Invited	Status	Add a comment
rndhpuser5 testuser	13/sep/2018 14:21 (Europe/Berlin)	Host	
rndhpuser1 testuser	13/sep/2018 14:23 (Europe/Berlin)	Invited	
rndhpuser2 testuser	13/sep/2018 14:23 (Europe/Berlin)	Invited	
rndhpuser3 testuser	13/sep/2018 14:24 (Europe/Berlin)	Invited	
rndhpuser4 testuser	13/sep/2018 14:24 (Europe/Berlin)	Invited	
	Type part of name	Invite	<u></u>





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Once accepted, the invited meeting member can join the meeting via the 'Timeline' or via ERN-Dashboard (s. page 38): 'My Meetings' or 'Panels'

	My Panels			2				
	Panel ID	Date	Nickname		My Meetings		2	
	#355	28/12/2017	nick		When	Title	Status	
	#672	01/08/2018	Solve-RD UR		14/sep/2018 14:17 (Europe/Madrid)	Case discussion	Invited	
	#662	27/07/2018	grower		30/sep/2018 01:00 (Europe/Madrid)	testttt	Host	
	Contributing Panels			2				
	Panel ID	Date	Nickname					
	#657	24/07/2018	cherry					
	#648	03/09/2018	cherry					
Meeting: Case discussion	#704	31/08/2018	Ball					×
Date & Time Participants Summ	mary						Test video Join Meeting	Meeting comments
							[⊮ Edit	Add a comment
		Title of meeting:	Case discussion					
		Description:						
		Meeting Status:	Upcoming					
		When:	14/sep/2018 14:17 (Europe/Berlin) 14/Sep/2018 12:17 (UTC)					
		Duration:	15 minutes					
		Meeting Panel:	yellow					
	During	the meetin				9 4 0 1		
	• Hi	de panel	ig you call.		rndhpuser5 testuser			Close

- Toggle full screen, camera, microphone •
- Share screen •
- Show chat, users •
- Start recording •





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- □ When the meeting has finished, the host should:
- Change the meeting status to 'finished' via the 'Date & Time' tab
- Record a meeting summary via the 'Summary' tab (s.next page)

Date & Time Pa	Participants	Summary				Test video Join Meeting	Meeting com	nents	
						🔶 🕼 Edit	Add a comment	:	
				Title of meeting:	Case discussion	-			
				Description:					
				Meeting Status:	Upcoming				
				When:	14/sep/2018 14:17 (Europe/Berlin 14/Sep/2018 12:17 (UTC))			
				Duration:	15 minutes				
				Meeting Panel:	yellow				
								Cle	ose
g: Case discussion	Summary			١			Test	Cit video Join Meeting	OSE Meeting comments
g: Case discussion	Summary		Title of meeting:	Case discussion			Test	Cit video Join Meeting	Meeting comments Add a comment
g: Case discussion Time Participants St	Summary		Title of meeting: Description:	Case discussion			Test	Cl	Meeting comments Add a comment
g: Case discussion Time Participants St	Summary		Title of meeting: Description: Meeting Status:	Case discussion Upcoming Started Finished Cancelled			Test	Ci	Meeting comments Add a comment
g: Case discussion Time Participants St	Summary		Title of meeting: Description: Meeting Status: Yype of meeting	Case discussion Upcoming Started Finished Cancelled Part of ERN recurring meeting Individual meeting			Test	Clu video Join Meeting	Meeting comments Add a comment
g: Case discussion Time Participants St	Summary		Title of meeting: Description: Meeting Status: Type of meeting When:	Case discussion Upcoming Started Finished Cancelled Part of ERN recurring meeting Id/Sep/2018 12:17 (UTC)		14:17 Euro	Test	Clu video Join Meeting	Meeting comments Add a comment





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Mee	ting: Cas	e discussion	1		>	C.
						
Da	te & Time	Participants	Summary	Test video Join Meeting	Meeting comments	
Summ	iary has not	been recorded y	/et		Add a comment	





II CPMS ERN Dashboard



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- □ See all panels invitations (1a.)
- □ See all panels you are leading (1b.)
- □ See all panels you are contributing to (1c.)
- □ See all the tasks associated with any panel or meeting you are participating in (2.)
- □ See all meetings you are hosting or have been invited to (3.)

European Reference Networks	ERN ERN-RND	- Neurological Diseases				Centr	e ERN Map 🤉 🕹	rndhpuser1 testuser -
	😕 ERN-RND -	Neurological Diseases ເ	JSER: rndhpuser1 testuser					
Dashboard	Panel Invitations	1a.		2	Member Tasklist	2.		2
3-1	Panel ID	Date	Nickname		Nickname	Task		
Panels	#725	14/09/2018	yellow		#657 cherry	Please review the data and pro	vide your contribution	
					#657 cherry	If meeting "test" has finished pl	lease ensure meeti	
Tasklist	Urgent Panels			2	#657 cherry	Meeting "test" has been update	ed.	
iĝ.	There are no urgent	panels.			#662 grower	Please review the data that is p	rovided for this Panel.	
My Meetings					#355 nick	Please complete the Patient File	e for this Panel.	
Webinars	My Panels	•		2 - C	#704 Ball	Meeting "case discussion" has b	been updated.	
webinars	Panel ID	Date	Nickname		#648 cherry	Please complete the Patient File	e for this Panel.	
Preferences	#355	28/12/2017	nick		#725 yellow	You have been invited to join th	nis panel. Please A	
	#672	01/08/2018	Solve-RD UR					
	#662	27/07/2018	grower					
		_			My Meetings	•		2
	Contributing Panel	s 1c.		1	When		Title	Status
	Papel ID	Date	Nicknamo		14/sep/2018 14:17 (8	Europe/Madrid)	Case discussion	Invited
	#657	24/07/2018	cherny		30/sep/2018 01:00 (8	Europe/Madrid)	testttt	Host
	#648	03/09/2018	cherty					
	#704	31/08/2018	Ball					





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□ Here you can view the panel, the consultation request, accept or refuse invitations







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Here you can see all the tasks associated with any panel or meeting you are participating in (e.g. Accept/Refuse a panel invitation, Accept/Refuse a meeting invitation, provide requested additional information on the patient

European Reference Networks	ERN ERN-RN	ID - Neurological Diseases		Centre	ERN	Мар	? -	🐣 rndhpuser1 testuser 🗸
	😕 ERN-RND	- Neurological Diseases USER: rnd	dhpuser1 testuser					
Dashboard	Task List							
9-9	Nickname	Assigned	Task					
Panels	#657 cherry	24/jul/2018 11:28 (Europe/Madrid)	Please review the data and provide your contribution					
> = •	#657 cherry	24/jul/2018 11:43 (Europe/Madrid)	If meeting "test" has finished please ensure meeting status is changed to finished and meeting s	ummary is r	ecorded.			
Tasklist	#657 cherry	24/jul/2018 11:47 (Europe/Madrid)	Meeting "test" has been updated.					
iiiii	#704 Ball	31/aug/2018 12:01 (Europe/Madrid)	Meeting "case discussion" has been updated.					
My Meetings	#648 cherry	19/sep/2018 14:07 (Europe/Madrid)	Please complete the Patient File for this Panel.					
Wahinawa	#662 grower	19/sep/2018 14:49 (Europe/Madrid)	Please review the data that is provided for this Panel.					
webinars	#732 Grey	20/sep/2018 13:53 (Europe/Madrid)	Meeting "wfgrew" has been updated.					

Preferences



CPMS ERN Dashboard -3.'My Meetings' View



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Here you can see all meetings you are hosting or have been invited to





CPMS ERN Dashboard -*4.'Preference' View*



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□ Here you can enter your preferences in any of the thematic areas listed

European Reference Networks	ERN ERN-RND - Neurological Disease	25	Centre ERN Map	? - 👌 rndhpuser5 testuser
	* ERN-RND - Neurological Disease	S USER: rndhpuser5 testuser		
Dashboard Panels	 My Preferences My professional role: 	Surgeon		4 a. ▼
Tasklist	Thematic Area			Select all
i.	Atypical parkinsonian syndromes: Genetic PD, Mult	isystem Atrophy, Progressive Supranuclear Palsy, Corticobasal degeneration		
My Meetings	Cerebellar Ataxias and Spastic Paraplegias			V
	Choreas and Huntington's Disease			V
Webinars	Dystonias, paroxysmal disorders (nonepileptical on	es) and Neurodegeneration with Brain Iron Accumulation		
Preferences	Frontotemporal dementia			
	Leukodystrophies			V
				O Update My Preferences



ANNEX-Optional Sections in the Consultation Form



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Consultation form-4c. Episode Description



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Save

Close

41

All subsections of this section are based on using a specific coding system, writing a free text or uploading an attachment

Consultation Request	Episode Description		
Episode Description	History:	Text	
Rare Disease Diagnosis		Attachment	
Comorbidities			
Phenotype/Genetic Features and Biobanks	Main Symptoms:		
E Family History		medDRA	
Health Behaviours		ICD-10	
Allergies and Other Adverse Reactions		Text	
History of Past Illness and Disorders		Attachment	
Special Treatment Intervention			
Surgical Procedures	T <u>Add main symptom</u>		
Transplantation History	+ Add current treatment		
Medication Summary	+ Add exam finding		
C Others	+ Add laboratory findings		
Medical Documents	+ Add imaging finding		
	+ Add other finding		
	+ Add previous clinical trial participation		
	+ Add other information		





Consultation form-4d. Rare Disease Diagnosis



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42			
Consultation Request	ICD-10 classification:	Type value for auto-complete	Q
Patient Information	Orphanet nomenclature:	[Orphanet] 585: Multiple sulfatase deficiency	Q
Episode Description	Date of first symptoms onset:	2008	
🗲 🖉 Rare Disease Diagnosis 🛛 🔵	Date of current Diagnosis:	02/May/2012	
Comorbidities	Age at Diagnosis:	8 Years 4 Months	
Phenotype/Genetic Features and Biobanks	Status of current Diagnosis:	Active In Remission	
Family History		Resolved	
Health Behaviours		Relapse Other	
Allergies and Other Adverse Reactions	* Diagnosis Provider:	ERN member Affiliated ERN Member	
History of Past Illness and Disorders	Non-ERN member healthcare provider:	Non-ERN member St. losef Krankenhaus Bochum	
Special Treatment Intervention		-	
Surgical Procedures	Country of Diagnosing centre:	Type value for auto-complete	
Transplantation History	* Treatment Healthcare Provider:	eRN member	
Medication Summary		Affiliated ERN Member Non ERN member	
Others	EPN member healthrare provider.		
Medical Documents			
	Diagnostic Test Code:	V Text	
	Text:		
	Data of observation:	2000	
	Date of observation.		
	Result:	Click here to attach file 🕹	
OPTION	+ Add Current Disease Diagnosis Working Diagnosis		
191			Cancel Save

+ Add Current Disease Diagnosis



Consultation form-4e. Comorbidities



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Consultation Request	Comorbidities		
Patient Information	Search All Coding Systems	Type value for auto-complete	[
Episode Description	Diagnosis Code:		
🔽 Rare Disease Diagnosis 🛛 🔵	Diagnosis code.	○ ICD-10	
🗹 Comorbidities 🛛 🔵		CCC-3 Cther	
Phenotype/Genetic Features and Biobanks	+ Add comorbidity		
Family History	Aud comorbinity		
Health Behaviours			
Allergies and Other Adverse Reactions			Close Save
History of Past Illness and Disorders			
Special Treatment Intervention			
Surgical Procedures			
Transplantation History			
Medication Summary			
Others			
Medical Documents			





Consultation form-4f. Phenotype/Genetic Features and Biobanks



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	Phenotype/Genetic Features and Biobanks	
Consultation Request		
Patient Information	Genetic study performed:	
Episode Description		Text
Rare Disease Diagnosis	Gene Affected:	HGNC Symbols
Comorbidities		Text
Phenotype/Genetic Features and Biobanks	DNA Variant: DNA Nucleotide reference sequence (RefSeq Id/LRG Id):	Type value for auto-complete
Family History	DNA Nucleatide variant description	
Health Behaviours	Diva Nucleotide variant description.	e.g. g. 120470
Allergies and Other Adverse Reactions	RNA Variant:	•
History of Past Illness and Disorders	RNA Nucleotide reference sequence (LRG Id):	Substitution
Special Treatment Intervention		Duplication
Surgical Procedures	Protein Variant:	Insertion
Transplantation History	Protein sequence (RefSea Id/I RG Id):	Inversion
Medication Summary	riteri sequence (nelseq lo ene lo).	Conversion Deletion-insertion
Others	Protein variant description:	Alleles
Medical Documents	······································	Repeated Sequences
	Phenotypic Abnormality (HPO):	Splicing
	Other changes:	e.g. DNA methylation
	Allelic State:	
0 ₀	Somatic Mutation as included in COSMIC (RefSeq Id/LRG Id):	Type value for auto-complete
10 ₁ ,	Specimens stored at biobank:	
3,		



Consultation form-4g. Family History



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-	
Consultation Request	Family History
Patient Information	Consanguineous Parents? 💿 Yes 💿 No 💿 Unknown
Episode Description	Healthy carriers in the family? 💿 Yes 💿 No 💿 Unknown
🗹 Rare Disease Diagnosis 🛛 🗧	+ Add healthy carrier
Comorbidities	Other cases in the family? 💿 Yes 💿 No 💿 Unknown
Phenotype/Genetic Features and Biobanks	Kinship of Carrier:
🖉 Family History 🛛 🗧	
Health Behaviours	+ Add other case
Allergies and Other Adverse	Pedigree 0.022 DBA
History of Past Illness and Disorders	Affected Add text here Carrier Add text here
Special Treatment Intervention	
Surgical Procedures	
Transplantation History	Pproband
Medication Summary	
C Others	
Medical Documents	
	Use this section to upload and display Pedigree images into CPMS. Please note that only permitted formats can be displayed (i.e. PNG, and JPEG)
	Image: Click here to attach file 1
So,	Cancel Save
10.	
NA.	
Y A	



Consultation form-4h. Special Treatment Interventi Carl at led Lythe Connecting Europe Union

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Consultation Request	
Patient Information	
Episode Description	
Rare Disease Diagnosis	
Comorbidities	
Phenotype/Genetic Features an Biobanks	d
Family History	
Health Behaviours	
Allergies and Other Adverse Reactions	
History of Past Illness and Disorders	
Special Treatment Intervention	
Surgical Procedures	
Transplantation History	
Medication Summary	
Others	
Medical Documents	

	Special Treatment Intervention		
	Special Treatment:	Blood transfusions	
	Comments/Notes:	A+	0
ONA	Attachment:	Click here to attach file 🛓	



Consultation form-*4i. Transplantation History*



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Consultation Request			
Patient Information			
Episode Description			
Rare Disease Diagnosis	Transplantation History		
🗹 Comorbidities 📃			-
Phenotype/Genetic Features and Biobanks	Transplant Material:		
Family History	Transplant Material Description:		
Health Behaviours	Date of transplant:	dd/Mmm/yyyy 🗎	
Allergies and Other Adverse Reactions	+ Add transplantation		
History of Past Illness and Disorders			
Special Treatment Intervention			Cancel
Special Treatment Intervention Surgical Procedures			Cancel Save
 Special Treatment Intervention Surgical Procedures Transplantation History 			Cancel Save
 Special Treatment Intervention Surgical Procedures Transplantation History Medication Summary 			Cancel Save
 Special Treatment Intervention Surgical Procedures Transplantation History Medication Summary Others 			Cancel Save
 Special Treatment Intervention Surgical Procedures Transplantation History Medication Summary Others Medical Documents 			Cancel Save



Consultation form-4j. Medication Summary



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48			
Consultation Request			
Patient Information			
Episode Description	Medication Summary		
Rare Disease Diagnosis			
Comorbidities	Is the patient receiving medication for his/her rare disease?	Yes No No	
Phenotype/Genetic Features and Biobanks			
Family History	Medication for Rare Disease Description:		
Health Behaviours			
Allergies and Other Adverse Reactions	Active Ingredient (ATC):	Type value for auto-complete	
History of Past Illness and Disorders	If not ATC:		
Special Treatment Intervention	Strength:		
Surgical Procedures			
Transplantation History	The second se		
Medication Summary	Type of unit:		
Others	Frequency of intake:		
Medical Documents			
	End date: Duration of Treatment:	dd/Mmm/yyyy 🗎	
	Pharmaceutical Dosage Form:		
	Medication compliance:	Compromised execution (patients who are actively engaged in therapy, but use medication inconsistent with provider instructions, i.e. skipping dosages and splitting pills	
		Discontinuation (occurs when a patient stops taking a prescription too early)	
		Primary non-adherence (occurs when patient does not obtain prescribed medication)	
	+ Add orphan drug	Ves No	
07			
NAI	Form is incomplete		Cancel Save



Consultation form-4k. Medical Documents



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DOTION RI

Consultation Request	Medical Documents		
Patient Information	Use this feature to share Files and DICOM images with this Panel. The server can remove identifying data from DICOM images and CDA standard documents. You must remove all identify data from all other file types before uploading.		
Episode Description			
Rare Disease Diagnosis	Attach Files/Images Delete/Rename Files Bulk Upload	o the Fahel.	
Comorbidities			
Phenotype/Genetic Features and Biobanks			
Family History			
Health Behaviours		Save	
Allergies and Other Adverse Reactions	File Picker: Attach images and files	×	
History of Past Illness and Disorders	About attached files		
Special Treatment Intervention	The software will de-identify DICOM images. The software will remove identifying sections from attached CDA documents. However, it may be unable to remove data completely. The software will not attempt to modify other document types.		
Surgical Procedures	When you share this Panel with FRN members, the attachments will be shared automatically.		
Transplantation History	When you share and rance were end internet by the dealerments will be shared automatically.		
Medication Summary	By ticking this checkbox, you confirm that no identifiable personal data are present in the uploaded file(s). If you consider the files		
C Others	screen with other participants.		
Medical Documents			

Close