

IQICC – QI in Crohn's & colitis

User Guide for the IBD Registry KPIs Tool (V01)

Using our secure web application for
capturing the essential data needed
for the new KPIs

Corresponds to IQICC release 1.0

This tool was created using grant funding provided by Galapagos



What are the revised KPIs ?

- The original clinical KPIs were focused on Biological Therapies
 - Started as part of the RCP Audit
 - Migrated to continue under the IBD Registry
- BSG IBD Section led the review of the KPIs in 2021
 - 2 Delphi rounds, across all UK
- Revised KPIs consensus focusing on
 - Diagnostic Pathway
 - Steroids Use
 - Biological Agents
- Published 2023 in Frontline Gastroenterology
 - <https://fg.bmj.com/content/14/5/407>


Why a KPIs Tool ?

- To support IBD teams without any other system for data capture
- KPI-focused data capture
 - Fast & easy data entry for KPI-level data
 - Auto calculations for KPIs immediately available
- Designed to help your local service
 - Worklists and reports, downloadable locally
 - Dashboard, service level and national comparators
- Can be extended to offer more options
 - Higher level QI, research and PROMS fields 'built in' if required
 - Can add to existing data for studies rather than start data entry again

What is REDCap ?

- REDCap is a widely used secure web application for research and studies data collection.
- The IBD Registry team will create an account for you
- Login here: <https://surveys.ibdregistry.org.uk/redcap/>
- Select "**IQICC Clinical KPIs**" Project
- After logging in, Help & FAQ (with searchable questions) and video tutorials are available in the left navigation menu.

Recommend to
view "Data Entry
Overview" video



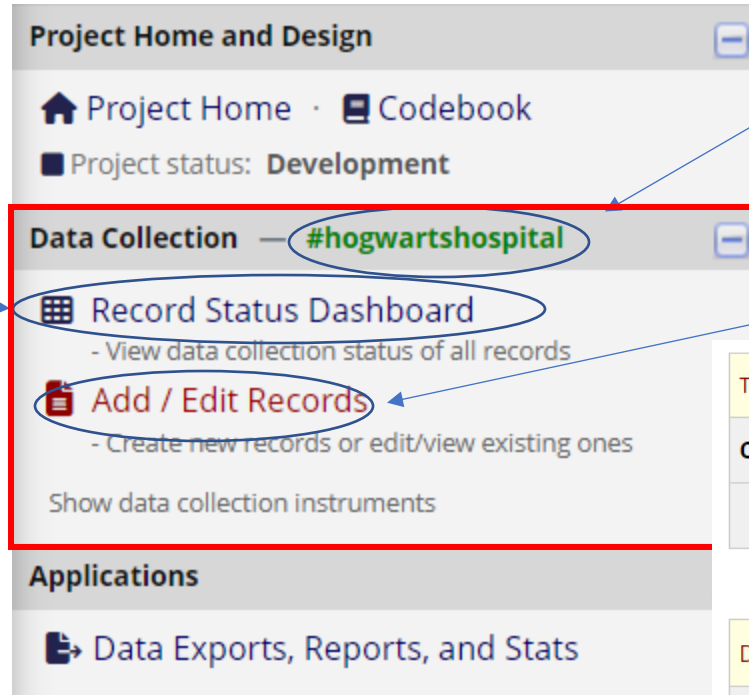
Using the screens for data capture

Data Entry Guidance

- Please **save** the form whenever leaving the page – this ensures that data is saved, and behind-the-scenes calculations are correctly performed.
- The forms/ instruments can be accessed and filled **in any order**. However, KPI information may be missing if insufficient data has been entered.
- Some fields have ‘soft’ validation with warnings (e.g. date of symptoms should be before date of diagnosis). But data can still be saved in case of rare edge cases – **please check the data makes clinical and logical sense before bypassing warnings**.

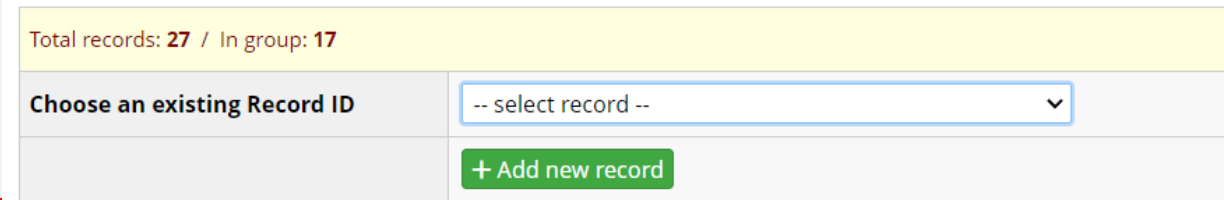
Landing Page - the Menu

Record Status Dashboard – click to view overview of patients' data collection status. Useful to quickly view and access a record's specific data entry form (instrument)

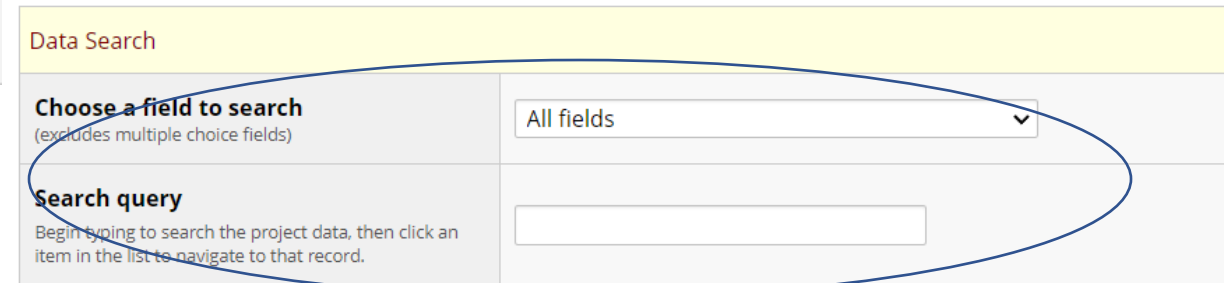


Your unique site identifier. You can only view and access records within your site/ hospital

Add/ Edit Records – page below:



Select existing record or add new record



Search for records by field values e.g. NHS number or Diagnosis

TIP! Press the Three Dots button to show/ hide the side menu



IQICC Clinical KPIs

PID 84

Understanding the Record Home Page

This page is accessed whenever you click a record by ID or click "add new record"

+ Add new record

Record Home Page

Record "1005-6" is a new Record ID. To create the record and begin entering data for it, click any gray status icon below.










The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event.

Legend for status icons:

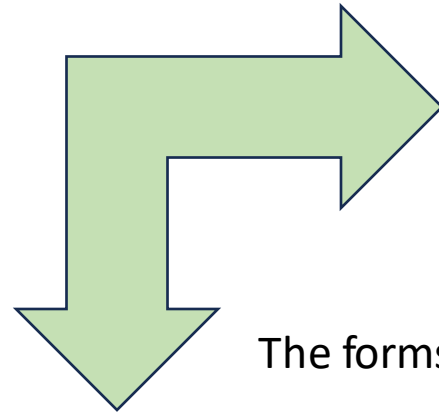
- Incomplete
- Unverified
- Complete
- Many statuses (mixed)
- Incomplete (no data saved) ?
- Partial Survey Response
- Completed Survey Response
- Many statuses (all same)

View the status of a form using colour status

NEW Record ID 1005-6

Data Collection Instrument	Status
Personal	
Diagnosis	
Medications	
Pre-Treatment Screening	
Advanced Therapies	
Summary	
Admin	
PROM (survey)	
Patient Consultation	

Click any status icon to enter/modify data for that form (instrument). Note that some forms are repeatable e.g. multiple medications can be entered



The forms each correspond to an element of patient engagement

Patient

Diagnosis

Medications

Pre-Treatment Screening

Advanced Therapies

Summary

Admin

PROM

Patient Consultation

Understanding the Record Home Page

Scroll page down to see summary information for this patient

Record Home Page

Record ID **1005-7** CONTRARY, Mary
DoB: 03-04-1956 NHS no: 8744413769
Diagnosis: Crohn's Disease

Data Collection Instrument	Status
Personal	<input checked="" type="radio"/>
Diagnosis	<input checked="" type="radio"/> +
Medications	<input checked="" type="radio"/> +
Pre-Treatment Screening	<input checked="" type="radio"/> +
Advanced Therapies	<input checked="" type="radio"/> +
Summary	<input type="radio"/>
Admin	<input type="radio"/>
PROM (survey)	<input type="radio"/>
Patient Consultation	<input type="radio"/>

Repeating Instruments

Diagnosis (1)

1	<input checked="" type="radio"/> Crohn's Disease Date: 05-06-1990
---	---

+ Add new

Medications (3)

1	<input checked="" type="radio"/> BUDmmx Start: 02-08-2022 End: 02-11-2022
2	<input checked="" type="radio"/> Adc Start: 12-08-2014 End:
3	<input checked="" type="radio"/> Aza Start: 01-03-2023 End:

+ Add new

Pre-Treatment Screening (1)

1	<input checked="" type="radio"/> Date: 08-08-2023
---	---

+ Add new

Advanced Therapies (2)

1	<input checked="" type="radio"/> Remsima Start: 11-01-2023 End:
2	<input checked="" type="radio"/> Certolizumab Start: 08-08-2023 End:

+ Add new

Click **+ Add new** to enter additional information for this patient

Patient → Diagnosis → Medications → Pre-Treatment Screening → Advanced Therapies → Summary → Admin → PROM → Patient Consultation

The Record Status Dashboard

Only patients for the user's clinical service shown

At-a-glance patient descriptor as index

Record ID	Personal	Diagnosis	Medications	Advanced Therapies	Summary	Admin	Data Submission	PROM	Admin test
8 ABBOTT, Hannah DoB: 21-01-2003 NHS no: Diagnosis: UC	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
995-3 ABERNATHY, Havmitch DoB: 01-01-1973 NHS no: 12345678812 Diagnosis: CD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
994-4 CONTRARY, Mary DoB: 04-03-1978 NHS no: Diagnosis: UC	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
994-1 EVERDEEN, Katniss DoB: 01-01-1973 NHS no: 11234567881 Diagnosis: CD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
994-3 GREEN, Christopher DoB: 15-04-1996 NHS no: Diagnosis: UC	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
994-2 MELLARK, Peeta DoB: 01-01-1973 NHS no: Diagnosis: CD	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 GRANGER, Hermione DoB: 02-09-1993 NHS no: Diagnosis: UC	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
994-3 GREEN, Christopher DoB: 15-04-1996 NHS no: Diagnosis: UC	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
13 HAGRID, Reubeus DoB: 01-09-2002 NHS no: Diagnosis: CD	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
29 HAWTHORNE, Gale DoB: 02-04-2023 NHS no: Diagnosis:	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
19 LUPIN, Remus DoB: 06-12-1984 NHS no: Diagnosis:	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Easy to navigate set of options for data

R-Y-G key to record completion

Repeatable items: how to add a new instance

Diagnosis

Current instance: 1 - Crohn's Disease Date: 15-03-2018

Editing existing 1 - Crohn's Disease Date: 15-03-2018 DoB: 01-01-1960 NHS no: 1234567881 Diagnosis: Crohn's Disease

Record ID 1005-6

+ Add new

Diagnosis

Diagnosis *required Crohn's Disease

Date of diagnosis *required

From the instance
dropdown

From the record home page

Repeating Instruments

Diagnosis (1)

1	Crohn's Disease Date: 15-03-2018
---	----------------------------------

+ Add new

Medications (2)

1	BUDF Start: 02-08-2022 End: 31-08-2022
2	Sal Start: 01-06-2023 End: 14-06-2023

+ Add new

From the
record data
collection
menu

Record ID 1005-6

KENT, Clark DoB: 01-01-1960 NHS no: 1234567881 Diagn

Select other record

Data Collection Instruments:

- Personal
- Diagnosis +
- Medications
- Pre-Treatment Screening
- Advanced Therapies
- Summary
- Admin
- PROM
- Patient Consultation



Diagnosis, Medications, Pre-Treatment Screening, Advanced Therapies, PROM are repeatable instruments. Meaning you can add multiple instances of them per patient. This may be required to perform accurate KPI calculations e.g. repeating steroid courses for an accurate KPI 3 (number of steroid courses last year)

Patient details – Personal

Basic patient information. Only name, DOB and NHS Number are required.

Personal

Adding new Record ID 1005-6.

Record ID 1005-6

Personal details:

First name *required Clark

Last name *required Kent

Date of birth *required 01-01-1960 D-M-Y

NHS/CHI/HSC number *required 1234567881

NHS number is valid.

Contact details

Email clark.kent@ibdregistry.com

Mobile 07123456789

Postcode

Save & Exit Form Save & Stay - Cancel -

NHS Number checker – feedback provided on screen for both valid and invalid inputs (warnings can be bypassed)

Diagnosis (KPI-1 & 2)

Diagnosis and date of diagnosis is required

Diagnosis

Editing existing Record ID **1005-6**. (Instance #1) KENT, Clark DoB: 01-01-1960 NHS no: 1234567881 Diagnosis:

Record ID 1005-6

Diagnosis

Diagnosis *required Crohn's Disease

Date of diagnosis *required 15-03-2018 D-M-Y Date is approximate

Diagnosis during non-elective admission? *Diagnosis received following an acute (non-elective) hospital admission*

Yes

No

Not Known

clear

KPI 1: Time from primary care referral to diagnosis in secondary care

Date of initial referral 25-01-2018 D-M-Y Date is approximate

Source of referral

General practitioner

Emergency department

Secondary care

Not Known

clear

KPI 2: Time to treatment recommendation following a diagnosis

First treatment during non-elective admission? *First treatment received following a diagnosis as an inpatient following an acute (non-elective) hospital admission*

Yes

No

Not Known

Date first treatment recommended 02-04-2018 D-M-Y Date is approximate

Outcome of treatment decision

Medication

Watch and wait

Patient declined treatment

clear

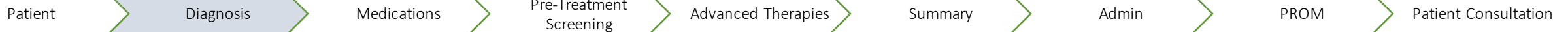
Save & Exit Form Save & Stay

- Cancel -

KPI 1 – date of initial referral is required for tool to calculate KPI

KPI 2 – date of first treatment recommendation is required for tool to calculate KPI

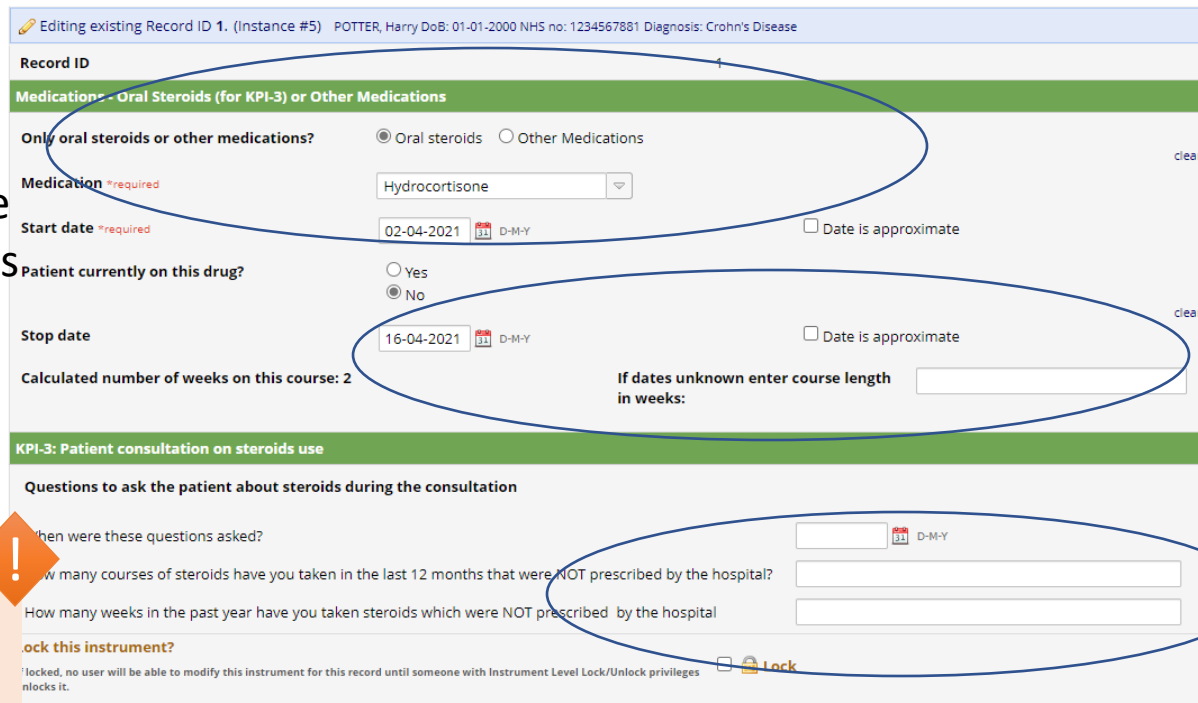
This is a REPEATABLE instrument. You can add another instance of the form if required. E.g. patient had unspecified IBD type before being diagnosed with Crohn's Disease.



Medications (KPI-3)

Medication & Start date required

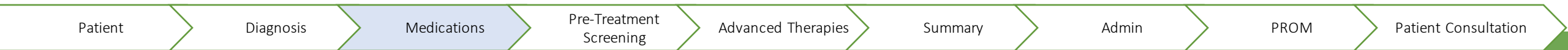
Medication list may be limited to only steroids if KPI-level selected



KPI 3 – tool will calculate the number of courses and weeks of steroids in the past year using all relevant instances of Medications.

KPI 3 – extra information can be provided from the patient

This is a REPEATABLE instrument. You can add another instance of the form if required. E.g. if the patient had multiple courses of steroids.



Pre-Treatment Screening

Pre-treatment screening prior to advanced therapies is required as part of KPI 4

Pre-Treatment Screening

Editing existing Record ID **1005-6**. (Instance #1) KENT, Clark DoB: 01-01-1960 NHS no: 1234567881 Diagnosis: Crohn's Disease

Record ID: 1005-6

Date of review *required: 16-05-2019 Date is approximate

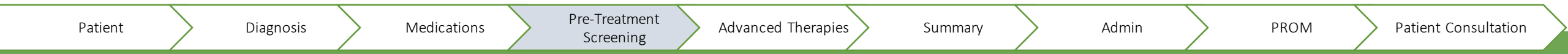
Screening tests	Yes	No	Not indicated	Not known	
CXR *required	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	clear
HBV serology *required	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	clear
HCV serology *required	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	clear
HIV serology *required	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	clear
TB test *required	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	clear
Lipids *required	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	clear

Buttons: Save & Exit Form, Save & Stay, - Cancel -

This is a REPEATABLE instrument. You can add another instance of the form if required. E.g. if the patient had multiple screenings



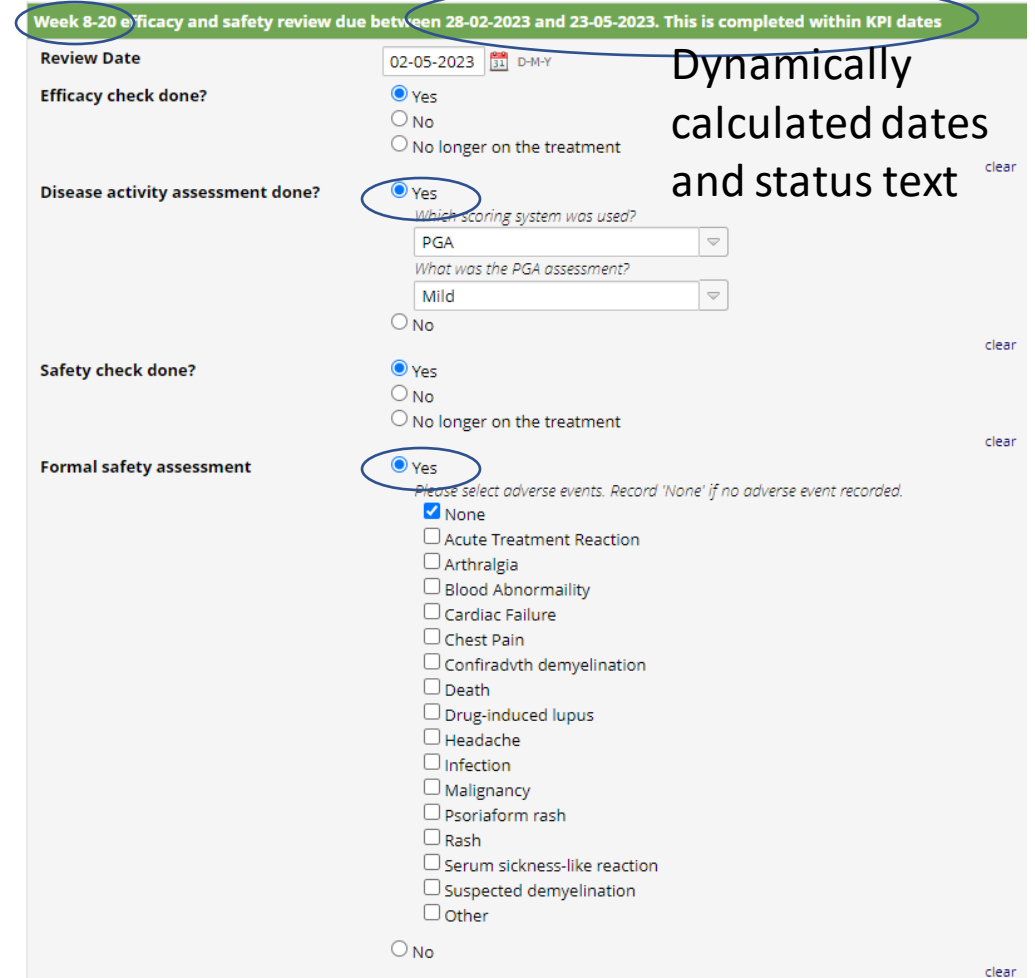
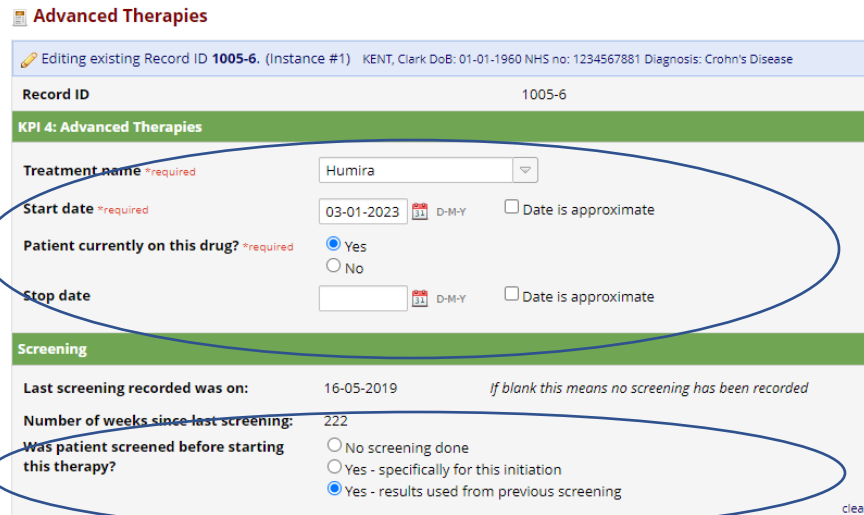
Lipids for JAK-i



Advanced Therapies (KPI-4)

Treatment name and dates are required

Screening question used for the later summary page

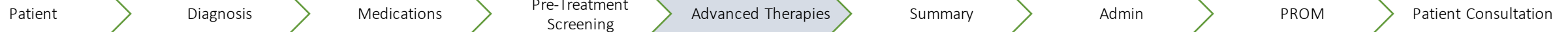


Dynamically calculated dates and status text

This is a REPEATABLE instrument. You can add another instance of the form if required. E.g. if the patient had multiple treatments



KPI 4 – two identical sections for the efficacy and safety review, one for 8-20 week, and one for 10-14 month. Dynamically shows fields if “Yes” selected for assessment.



Administration (for senior users)

Senior clinical users can decide what level they want the data screens to show at

Please select the level of data you want to collect in this tool
This will change the data collection fields that are displayed to you

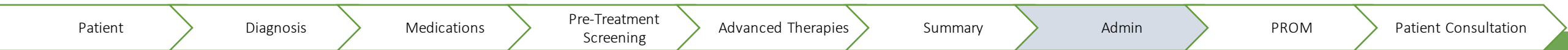
- Basic KPI data only
- Quality Improvement (includes KPIs)
- Research level data

clear


Simple KPIs only – for services wanting just to collect data for KPIs

KPIs-plus – for services on existing tools wanting to switch in but wanting to keep current data

Research – for services wanting to collect a higher level of data for research, on specific patients (i.e. you don't have to change the whole service)



Summary screen

 Editing existing Record ID **1005-6**. KENT, Clark DoB: 01-01-1960 NHS no: 1234567881 Diagnosis: Crohn's Disease

Record ID 1005-6

Patient Summary for Clark Kent

Name **Clark Kent**

NHS/CHI/HSC Number **1234567881**

DoB **01-01-1960**

Current diagnosis **Crohn's Disease** Earliest diagnosis **CD**

Date of diagnosis **15-03-2018** Date of earliest diagnosis **15-03-2018**

Date of referral **25-01-2018**

First treatment started **02-04-2018**

Date Consented _____

Sex _____ Gender (if different from sex) _____

Family history IBD _____ Family history colorectal _____

Email **clark.kent@ibdregistry.com** Postcode _____

Mobile **07123456789** Preferred contact method **TBC**

Steroid Treatment Summary for Clark Kent

Currently on steroids?	No	Number of courses in total	2	Number of weeks on steroids in past year	1
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Advanced Therapies Summary for Clark Kent

Currently on advanced therapy?	Yes	Drug name*:	Humira	Date started:	03-01-2023
3 month check	completed within KPI dates	Date due between*:	28-02-2023 and 23-05-2023		
12 month check	upcoming	Date due between*:	03-11-2023 and 03-03-2024		

KPIs Summary for Clark Kent

A guide to the KPIs is below the table

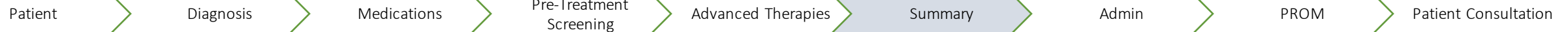
KPI-1	Days between most recent diagnosis and primary care referral	49
KPI-2	Days between most recent diagnosis and treatment recommended	18
KPI-3	Steroids	
3a	Number of steroid courses in the 12 months before 04-10-2023 [†] (excludes patient reported)	0
	Patient reported number of steroid courses in the 12 months before _____ [‡]	_____
3b	Number of weeks on steroids in the 12 months before 04-10-2023 [†] (excludes patient reported)	0
	Patient reported weeks on steroids in the 12 months before _____ [‡]	_____
KPI-4*	Advanced therapies pre-screening and assessment	
4a*	Pre-screening status	Yes - results used from previous screening
4b*	Week 8-20 review date	02-05-2023
4c*	Month 10-14 review date	_____

* most recent treatment started

[†] This is the KPI year end date which can be adjusted in the "Admin" instrument. If no date is set, calculations are made from the date the record was last saved in REDCap.

[‡] This is the most recent date when patient was asked about non-prescribed steroids

Summary of KPIs for the patient. Information may be missing if other instruments not completed



Worklists and Reports

Example KPI De-identified Report

KPI 1 for most recent diagnosis (days)	KPI 2 for most recent diagnosis (days)	KPI 3 end date - If not set in Admin, then this is the date the record was last saved	KPI 3 - Number of courses of steroids in the 12 months before KPI end date (excludes patient reported)	KPI 3 - Number of weeks on steroids in the 12 months before KPI end date (excludes patient reported)	KPI 4 - Screening status for most recently started advanced therapy	KPI 4 - 3m review date for most recently started advanced therapy	KPI 4 - 1y review date for most recently started advanced therapy
363	30	2023-10-02	2	17	Yes - results used from previous screening	2023-08-17	2023-08-17
	2	2023-08-02	1	13	Yes - results used from previous screening	2023-09-05	2023-09-07
		2023-09-18	0	17			
	30		0	0			
	114		0	0	Yes - results used from previous screening		
	61	2023-03-01	0	0	Yes - specifically for this initiation		
			0	4			
		2023-09-13					
160	7		1	11			
64	21		0	0	Yes - specifically for this initiation	2010-07-12	2011-05-09
92	34				Yes - results used from previous screening		
57	161	2023-09-25	0	1	Yes - specifically for this initiation	2023-09-25	
		2023-09-27					
		2023-09-29					
59	1099	2023-09-27	0	8			
			2	23			
	28		1	20		2023-08-01	
49	49	2023-09-20	1	23			
			1	23			
	2		1	52			
	20	2023-09-26	1	21	Yes - specifically for this initiation		
0	0	2023-09-20	0	0			

Dashboard

IQICC Dashboard

KPI Summary

Summary of KPI 1-4 for your site: _____

KPI 1 & 2 data in this summary below relate **to the latest diagnosis** for each record/patient.
KPI 3 data in the summary below relate to the 12 month window unique to each record (each record has individually configurable 12 month window which may be different).
KPI 4 data in this summary below relate **to the most recently started advanced therapy**.

Your Site KPI 1-3

	Count of Non-Missing Items	Missing	Min	Max	Mean	Median	StDev
KPI 1 for most recent diagnosis (days)	17	33	0	363	83.12	59	88.42
KPI 2 for most recent diagnosis (days)	32	18	0	8400	435.84	17	1598.0
KPI 3 - Number of courses of steroids in the 12 months before KPI end date (excludes patient reported)	32	18	0	2	0.530	0	0.620
KPI 3 - Number of weeks on steroids in the 12 months before KPI end date (excludes patient reported)	32	18	0	52	8.72	4	11.71

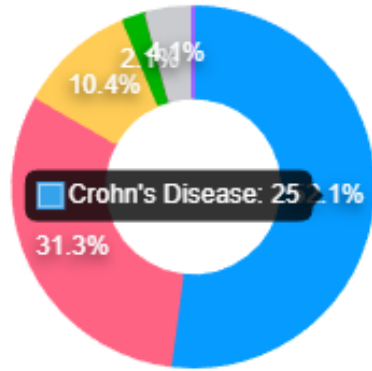
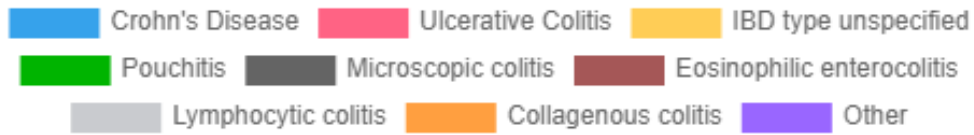
[Export table \(CSV\)](#)

The IQICC Dashboard provides a **live** statistical and visual overview of key data items for your site.

Use the tabs to navigate.

IQICC Dashboard

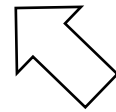
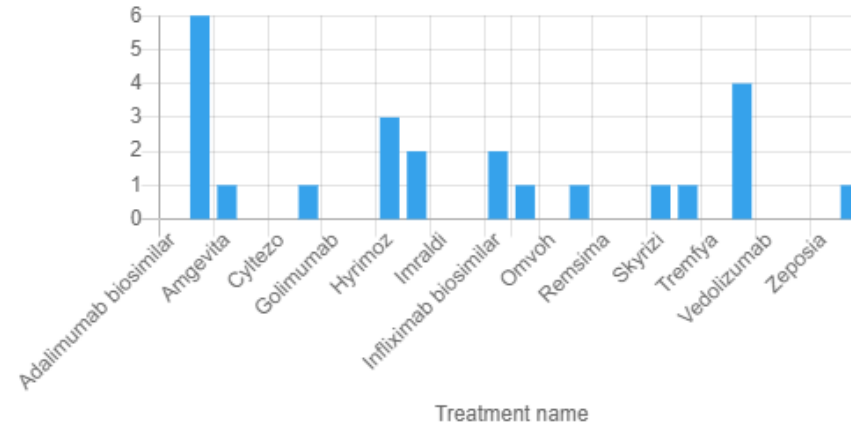
Most recent/ current diagnosis breakdown



[Enable color-blind accessibility](#)

Breakdown of therapies

Click chart for full details



All graphs are clickable to enlarge and hoverable with your cursor to view the actual value.

Registry Data Submission


WARNING: Export Permissions

Identifiable personal data

- Data containing identifiable information such as NHS number, date of birth, names, require explicit user permissions for export out of REDCap.
- Only senior/ trained clinical users are given permissions by our administrators to export identifiable data out of REDCap (for example to submit to the IBD Registry)
- You must follow your local Trust's Information Governance requirements when exporting and downloading personally identifiable data onto NHS trust devices.

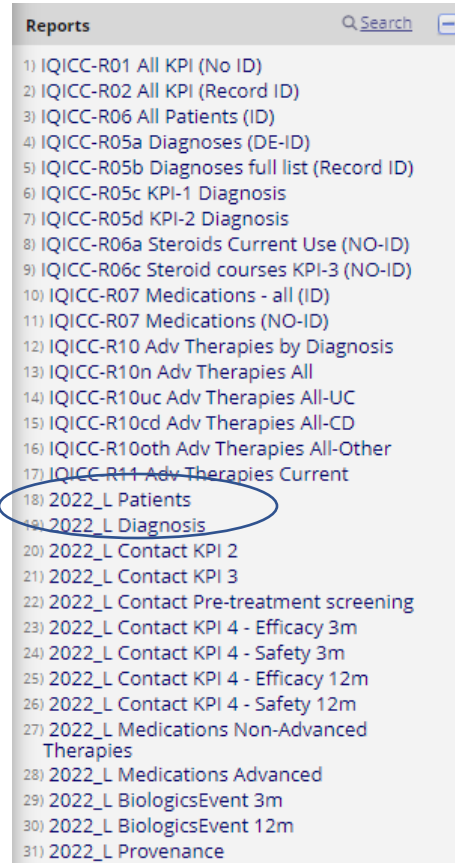
De-identification options (optional)

The options below allow you to limit the amount of sensitive information that you are exporting out of the project. Check all that apply. Given that you have 'De-Identified' or 'Remove All Identifier Fields' export rights for one or more data collection instruments, some fields may be automatically removed from the exported data based on your instrument-level Data Export Rights. Additionally, if you check any of the checkboxes for the settings below, that de-identification setting will be applied to all remaining fields in the resulting data export.



If you see this red text when exporting (during **step 3** in the next slide), then you are **NOT** able to export identifiable fields of data. The resulting export is **NOT** compatible with IBD Registry submission. For help with user roles and permission please email: support@ibdregistry.org.uk

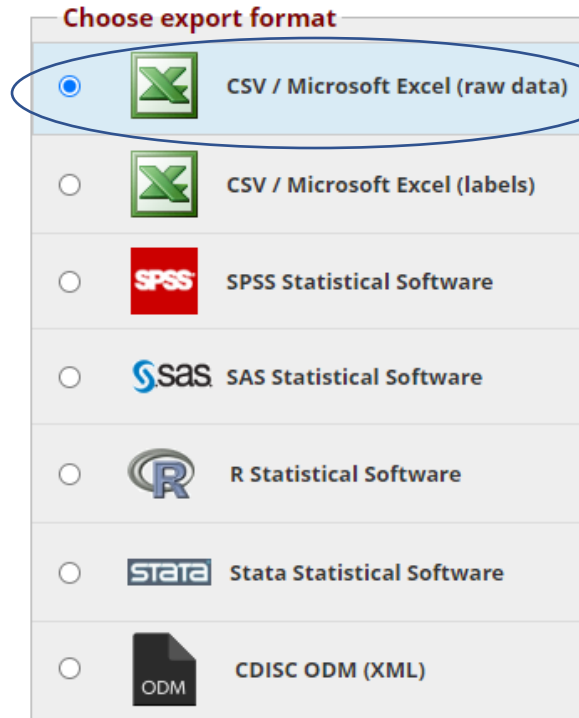
Exporting files for IBD Registry submission



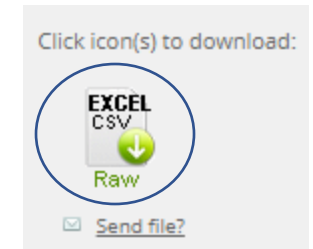
2) Press Export Data



1) Select a 2022_L report – this is a registry compliant submission report to be exported

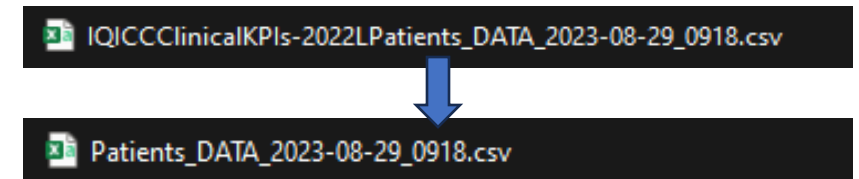


3) Select CSV (raw data) -> Press Export



4) After successful export, click icon to download the csv file

5) Rename the file by deleting "IQICCClinicalKPIs-2022L" in the filename



Any questions ?

Contact the IBD Registry team
support@ibdregistry.org.uk

Version Control

Date	Version Number	Description of Changes
25-10-2023	V01	Original Release