russreadbarrow@gmail.com · linkedin.com/in/russellrb · @fcancerwith.ai · fcancerwith.ai/my-one-view

CANCER PATIENT LAB · HACKATHON · 25 NOV 2026

Planning my next move before I need it.

Russ Read-Barrow · stage IV bowel cancer · five years in

GOAL FOR TONIGHT

Keep building my care circle, share where I am, and get help with the questions and decisions ahead.

WHO I AM

Why I’m here



Katy, Lyla and Rex.

That’s what this is about, and what keeps me going.

FC:AI · ONE VIEW

Bowel cancer, stage 4

RAS · BRAF **Wild-type**	MMR **pMMR/MSS**
DRIVERS **APC · TP53**	CEA 24 NOV **82.3**

fcancerwith.ai/my-one-view

- I put my whole record online, on one page: One View
- It’s brought me oncologists, genomics, vaccine researchers, a Toronto imaging lab, the BBC and Nature
- Free to look at, free to copy

HOW TONIGHT WORKS

The start of a hackathon, not the end of one.

15 MIN · ME

The short version

Where I am, the decisions coming up, and who I'm looking for.

45 MIN · YOU

Over to you

Raise your hand or use the chat; Brad moderates. Pick any thread from the menu.

AFTER TONIGHT

It keeps going

Notes, deck and One View go to everyone, including people who couldn't make it tonight.

Bringing everyone together, so I'm not the one in the middle interpreting it all. The best outcome: anyone saying "I can help with that."

FIVE YEARS · 2021 TO NOW

It works every time. It comes back every break.

2021–22

XELOX + surgery

Bowel and liver resection. Severe oxaliplatin reaction, and progression on it: ruled out.

2023–24

Lung SABR, then ablation

SABR 2023. Six lung lesions ablated 2024.

2024–25

Chest nodes

Mediastinal disease, confirmed by EBUS.

2025

FOLFIRI + cetuximab ×6

Good partial response. Back after a 6-month break.

2026

Rechallenge ×6

Good response by May. Back in the break, July.

AUG–NOV 2026

Block 3

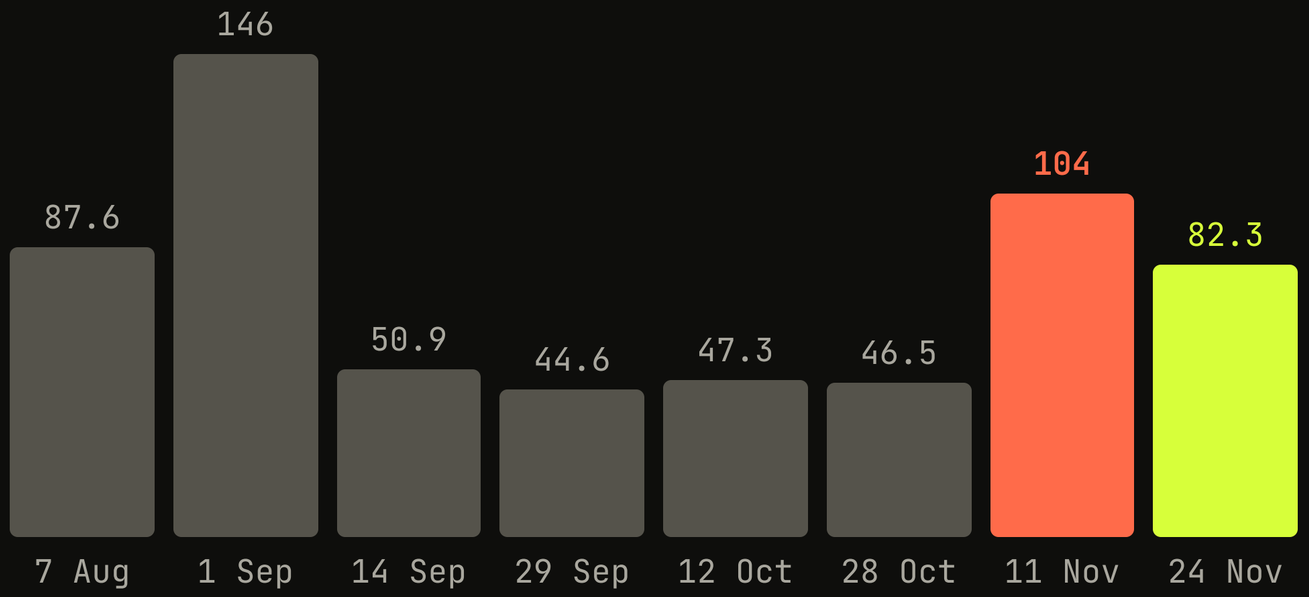
Partial response, CT 28 Oct. Irinotecan dropped 12 Nov. CEA up, then down.

Each response is a bit smaller. The pattern is the evidence, not just the biomarkers.

WHERE I AM TODAY

Scan shrinking. CEA up, then back down.

CEA µg/L · normal is under 5.2



104 on full FOLFIRI (11 Nov), 82.3 on maintenance (24 Nov). Next bloods 10 Dec.

SCAN · CT 28 OCT

Partial response in lungs and chest nodes. Liver stable.

TREATMENT

5-FU + cetuximab maintenance since 12 Nov. Irinotecan stopped. No oxaliplatin.

BIOMARKERS · OTHER

RAS/BRAF wild-type · MSS · TMB 3 · HER2 negative · APC · TP53 · UGT1A1 *28/*28 · smouldering myeloma · WHO PS 0

WHERE I NEED HELP

Three decisions coming in the next few weeks

1 · LOCAL TREATMENT

Mixed views

Lung: a specialist suggests a PET, then bronchoscopy to clear the airway. Liver: a surgeon, MRI 8 Dec if approved. My oncologist: none for now.

2 · TESTS AND TISSUE

What’s worth it?

Guardant 360 now or later? WGS, RNA and the rest: what to pay for, when, and what tissue to bank if I have a procedure.

3 · WHAT’S NEXT

After maintenance

Lonsurf + bevacizumab, or trials first? Personalised vaccines? Options outside the UK and US?

This deck holds more than I’ll go through tonight. We can jump to the detail, or I’ll follow up afterwards.

THE MAIN ASK · MY CARE CIRCLE

Who I’m looking for

ALREADY IN MY CIRCLE

Integrative oncologist
Radiation oncologist (US)
Oncologist (Albania)
Lung interventional specialist
Genomics: long-read, expression, cell states
AI imaging lab (Toronto)
Vaccine researchers
Microbiome and infection
Fellow patients

LOOKING FOR

- **UK or European bowel cancer oncologist** who knows the trials
- **Liver surgeon or interventional radiologist**
- **Bioinformatician** for my sequencing and RNA data
- **Immunologist** working on MSS immunotherapy
- **Clinical pharmacologist**: drug interactions, UGT1A1
- **Trial navigator** for UK and EU early-phase units
- **Functional testing lab** for my next tissue sample

Know someone, or could this be you? Say so in the chat, or email russreadbarrow@gmail.com. Who else should be on this list?

BEFORE YOU GO

Could you take one of these on?

1 · INTRODUCE

Make an introduction

To anyone in the roles on the last slide, here or not.

2 · RESEARCH

Look into one option

A trial, a test or a treatment we talked about.

3 · ANSWER

Answer one question

Tissue, sequencing, drug interactions, imaging.

4 · STAY

Give a little time

Join my care circle and weigh in now and then.

MOST URGENT, NEXT FEW WEEKS

The PET-CT and liver MRI decision · a tissue plan before any procedure · which trials to screen for before Lonsurf

Put your name in the chat, or email russreadbarrow@gmail.com. Afterwards I'll share this deck, my One View and a write-up with names against actions, including with people who couldn't join tonight.

TIME TO OPEN IT UP · 45 MIN **DISCUSSION**

Pick a thread

Thread (click to jump)	Slide
Local treatment: lung, liver, both or neither, and when?	→ 11
Tests: Guardant 360 now or later? What's worth paying for?	→ 12
Tissue: what to bank if I have a procedure, and how	→ 12
My data: what's missing, PTEN, who could analyse it	→ 13
Next treatments: trials before Lonsurf, vaccines, beyond the UK and US	→ 14
Side effects: cetuximab skin, sleep, hyperbaric oxygen	→ 15
My full record (One View): doses, genomics, bloods, scans, medicines	→ 16–20
Who else should be in my care circle?	→ 7

Thank you.

To Brad Power and Cancer Patient Lab, and to all of you, for your time and ideas. Keep in touch:

EMAIL	**russreadbarrow@gmail.com**
ONE VIEW	**fcancerwith.ai/my-one-view**
LINKEDIN	**linkedin.com/in/russellrb**
INSTAGRAM	**@fcancerwith.ai**
WEBSITE	**fcancerwith.ai**

BACKUP · LOCAL TREATMENT

I’m getting mixed views. What would you do?

LUNG · SPECIALIST

Blocked left upper lobe

CT reports since 2025: probable tumour inside the airway, the kind cryotherapy can clear. Suggests a PET, then bronchoscopy.

LIVER · SURGEON

One area, maybe two

MRI and surgical opinion pencilled in for 8 Dec, if approved. Treating it could open BOT/BAL.

MY ONCOLOGIST

No local treatment, for now

Too many sites; more lung radiotherapy could hurt my breathing. Away until next week; gets today’s questions.

Worth knowing: CEA 46.5 → 104 (full FOLFIRI) → 82.3 (maintenance) · ALP high Sept–Nov, normal now · one lung nodule has hollowed out: response, or infection?

- Lung, liver, both or neither? Should a PET-CT and the liver MRI happen first?
- If something is done, can it be timed around chemo, and what tissue should be taken?

BACKUP · TESTS AND TISSUE

What should I get, when, and why?

GUARDANT 360

Liquid biopsy. My insurer pays up to £2,000, once only. My oncologist leans towards waiting. When would you use it?

OTHERS HAVE SUGGESTED

Whole genome sequencing · whole-transcriptome RNA · long-read DNA and methylation · cell-state analysis · functional drug testing · an infection check, incl. fungal

WHAT I NEED TO KNOW

Which are worth it now, and which later? What tissue does each need? How much should I budget and save?

THE TISSUE QUESTION

If I have lung or liver treatment, now is the time to bank tissue for later. What do I ask for, how should it be stored, and who arranges it?

BACKUP · MY DATA

The data I can share

Data	What's in it	Format
Tumour gene panel	500+ genes, tumour-only: APC, TP53 with VAFs, TMB 3, MSS	Report + raw files (Exacta, 2025)
Pharmacogenetics	UGT1A1 *28/*28, DPYD, ERCC1, XPC	Report
Blood RNA and CTCs	Exosomal RNA expression; CTC drug-sensitivity assay	Report
Tumour tissue	Targeted RNA; ICC for mTOR, VEGFR, HMGB1	Reports
Bloods	27 draws, full CEA series, five years of treatment	CSV / JSON
CT scans	Full studies, Jul and Oct 2026	DICOM, anonymised on request
Daily tracking	Symptoms and side effects, cycle by cycle	Log, on request

UNDER WAY

Blood analysis with a vaccine research partner · UHN Toronto hoping to review my latest imaging

GAPS

No WGS yet. PTEN: a letter says variant, the report says none. Could the raw files settle it?

BACKUP · WHAT'S NEXT

My plan so far. What am I missing?

Maintenance → **Lonsurf + bevacizumab** → **Trials** → **Fruquintinib or regorafenib**

Option	Why it may fit	What to check
FOLFIRI + bevacizumab first	Irinotecan back, plus a first anti-VEGF	Keeps bev trials open; dose plan
Trials before Lonsurf	Several need patients who haven't had it	UK sites; myeloma exclusion
Botensilimab + balstilimab	MSS response without active liver mets	UK access, cost, the liver
Cetuximab rechallenge	Worked three times	When to use Guardant 360
Wnt peptides; BNT314 + BNT327	Target APC pathway; bispecific with UK sites	US only / eligibility
Personalised vaccines	More and more happening	When, how, cost in the UK?

Beyond the UK and US: treatments, places or people I should be looking at?

BACKUP · LIVING WITH IT

What a fortnight of treatment feels like

D1 Infusion	**D2** Pump · dex	**D3** Pump off	**D4** Dex	**D5** Tough	**D6** Hardest	**D7** Hardest · gut
D8 Turning · gut	**D9** Good	**D10** Good	**D11** Good	**D12** Good	**D13** Good	**D14** Bloods

SINCE DROPPING IRINOTECAN

Much easier

Mainly fatigue. Gut problems on days 7 and 8.

WHAT I CAN'T GET ON TOP OF

Skin under my eyes (cetuximab): sore, worse in cold and heat, nothing quite works.
Sleep: half a zopiclone at night, another half at 3am.

ALONGSIDE, INTEGRATIVE CARE

Metformin · atorvastatin · melatonin · mebendazole (started, fine) · hyperbaric oxygen: considering. Is it safe for me?

APPENDIX · FROM MY ONE VIEW, 25 NOV

Current treatment, cycles and doses

Drug	Dose	Status
Cetuximab	500 mg/m² (1000 mg)	Continuing
5-FU bolus	400 mg/m² (900 mg)	Continuing
5-FU 46-hour infusion	2400 mg/m² (5000 mg)	Continuing
Folinic acid	350 mg	Continuing
Irinotecan	180 mg/m² (400 mg)	Stopped after C6

Doses as given to C6 · BSA 2.08 m² · every 14 days

NOW

Maintenance since C7 (12 Nov): 5-FU/folinic acid + cetuximab, to progression.

CYCLES SO FAR

C1 19 Aug · C2 2 Sep · C3 16 Sep · C4 30 Sep · C5 14 Oct · C6 29 Oct · C7 12 Nov

COMING UP

C8 26 Nov · C9 10 Dec · no chemo 24–30 Dec · C10 31 Dec

APPENDIX · FROM MY ONE VIEW, 25 NOV

Molecular profile and pharmacogenetics

Marker	Result
KRAS / NRAS / BRAF	Wild-type
MMR	pMMR / MSS
HER2 · PD-L1	IHC 0 · under 1%
TMB	Low, 3 mut/Mb
APC	p.S1415Rfs*4 (tissue 8.5%, cfDNA 0.62%)
TP53	p.R342* (tissue 9.21%)
VUS	RUNX1T1, FANCM, CIC, BCR, CYP2D6
Exploratory	MTOR, VEGFR1/2 positive; HMGB1 high

PHARMACOGENETICS · SEP 2025

UGT1A1 *28/*28: poor metaboliser (irinotecan toxicity; Gilbert's) · DPYD normal · ERCC1, XPC: platinum toxicity risk

LAB CELL-KILL ASSAY

5-FU 65% · oxaliplatin 50% · trifluridine 39% · irinotecan 37% · CTCs 1/ml. In vitro, not proof it works in me.

SMOULDERING MYELOMA

IgG kappa; free kappa 22.8 mg/L (ref 3.3–19.4), Jun 2025. May affect trial eligibility.

APPENDIX · FROM MY ONE VIEW, 25 NOV

Bloods on 24 Nov, and how I'm doing

Test	24 Nov
CEA (µg/L)	**82.3**, from 104 (11 Nov) and 46.5 (28 Oct)
ALP (U/L)	97, from 166: back in range
Bilirubin (µmol/L)	28, high (Gilbert's)
Haemoglobin (g/L)	123, marginally low; RBC, HCT too
White cells · neutrophils	7.00 · 4.29 · lymphocytes 1.66
Platelets	271
Liver	ALT 35 · AST 27 · GGT 24 · albumin 41
Kidney · salts	eGFR over 90 · Na 136 · K 4.3 · Mg 0.90

DAILY TRACKING · 20 AUG–25 NOV

89 of 98 days logged. Mood 6.8/10, energy 5.7/10 on average. Dips after each infusion; the floor has risen since irinotecan stopped.

NOT SOLVED YET

Rash around the eyes, not responding. Zopiclone on 15 of the last 25 logged days.

APPENDIX · FROM MY ONE VIEW, 25 NOV

Five years of treatment and scans

TREATMENT

Dec 2021–Feb 2022 XELOX ×4: good partial response
Mar–Oct 2022 Primary and liver met resected (R0); adjuvant CAPOX
Oct 2022–Apr 2023 Lung mets; SABR 55 Gy/5
Jun and Aug 2024 Lung ablations
Feb 2025 EBUS: mediastinal nodes
Apr–Jul 2025 FOLFIRI + cetuximab ×6: good partial response
Feb–May 2026 Rechallenge ×6: good response
Aug 2026 on Third block after progression in the break

SCANS

6 Jan 2026 Mild progression; severe left upper lobe bronchial narrowing
12 May 2026 Good response, chest and lungs
19 Jun 2026 CT head: normal
23 Jul 2026 Progression above and below the diaphragm; new liver lesion, segment 7
28 Oct 2026 Partial response, lungs and chest nodes; liver stable; one right upper lobe nodule has cavitated

APPENDIX · FROM MY ONE VIEW, 25 NOV

Medicines, and my oncologist's latest letter

CHEMO DAY

Akynzeo, dexamethasone, chlorphenamine, atropine. Pegfilgrastim 24 hours after.

SUPPORTIVE

Dexamethasone ×3 days, domperidone, loperamide, doxycycline + Plazon (skin), Laxido, antihistamine, zopiclone as needed.

OTHER

Citalopram, melatonin, metformin MR 500 mg twice daily, loratadine. Since: mebendazole. Paused: mistletoe, most supplements.

CLINIC LETTER · 2 NOV 2026

Further response at known sites. Irinotecan left out from C7; maintenance to progression. No local treatment indicated. Next line Lonsurf + bevacizumab, with trials considered first. Genome sequencing not funded; a liquid biopsy is an option. Smouldering myeloma may affect trial eligibility.