



A Cancer Patient-centred data environment

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MPNE and MelanomeFrance



CDDF
MULTI-STAKEHOLDER
WORKSHOP

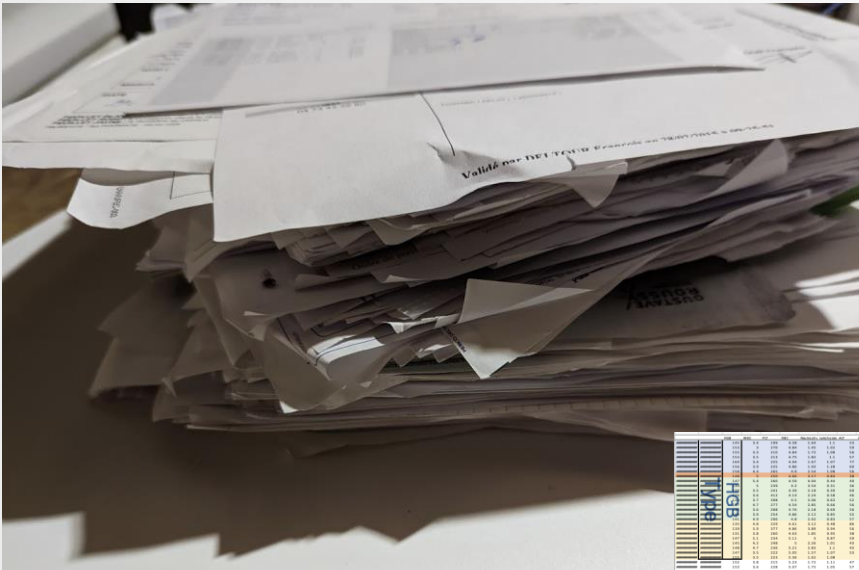
Patient Access and Engagement in
Oncology Drug Development

19 - 20 September 2022

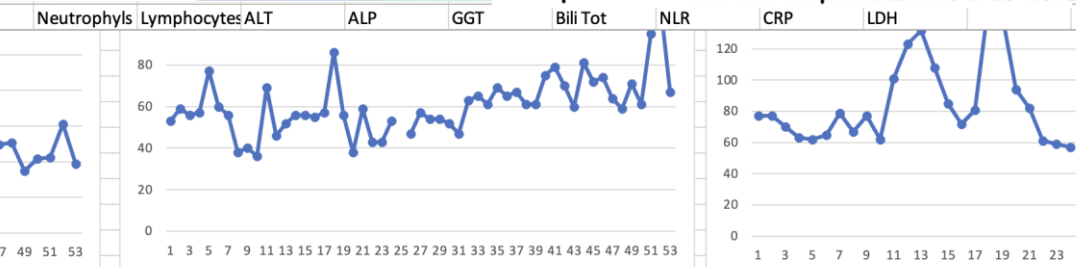
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HEALTH RECORDS & ANALYTICS



Sample Type	SODIUM	POTASSIUM	UREA	CREATININE	GLUCOSE	ALANINE TRANS.	ALK. PHOS.	GAMMA G.T.	BILIRUBIN, TOTAL	PROTEIN, TOTAL	ALBUMIN	CALCIUM	CALCIUM(ADJUST)	PHOSPHATE (as P)	MAGNESIUM	URATE
140	3.7	5.0	91		53	77		11	68	41	2.27	2.15			0.76	
137	3.2	6.0	105		59	77	60	13	71	40	2.34	2.24			0.86	
141	3.8	6.2	110	7.8	56	70	50	14	67	42	2.28	2.14			0.79	
141	3.7	7.8	102		57	63		15	68	43	2.31	2.15				
141	4.1	5.4	106	5.6	77	62	85	14	69	44	2.29	2.11			0.80	
142	4.0	7.7	109	5.6	60	65	55	12	70	46	2.32	2.10			0.80	
144	3.9	7.1	99	4.6	56	79	46	14	74	47	2.40	2.16			0.77	
140	4.5	4.2	87	5.5	38	67	38	18	70	39	2.25	2.17			0.76	
141	4.2	5.1	98		40	77		16	66	36	2.26	2.24	1.27		0.78	
138	4.1	5.5	99		36	62		13	61	35	2.08	2.06	1.12		0.71	



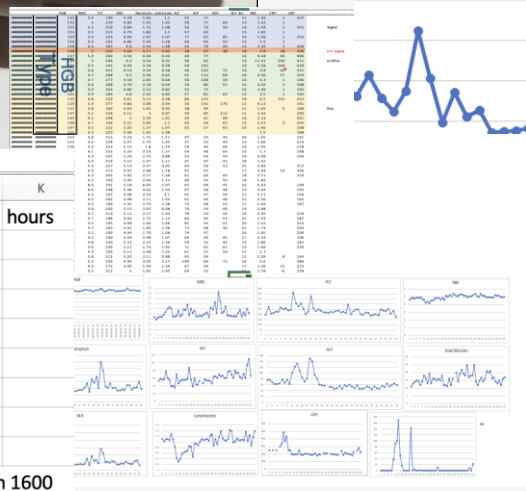
MRI Head with contrast
MRI Spine whole

Clinical information:
Melanoma. Lesion T12.

Findings:
Comparison is made with the previous MRI of 29 Nov



E	F	G	H	I	J	K
Imaging	bloods	biopsies	surgery		Travel	hours
2	2		2		800	
3 monthly	monthly	3	1		800	
					800	
					800	
3					800	
3					800	
3		3			800	
3 plus 2		4			800	
			1		800 til oct then 1600	
					1600	
					1600	
3						
6						



79	46	14	2.35	1	299
67	38	18	3.8	38	336
77		16	9.18	90	486
62		13	11.41	100	371
101		19	5.58	168	429
123	71	13	3.8	5	274
132	68	16	3.26	17	284
108	59	16	4.3	1	108
85	55	15	3.16	1	85
72		16	2.49	1	72
81	63	15	3.5	1	81
152		18	6.5	142	207
141	176	12	4.13	5	141
94		12	1.95	5	94
82	112	11	3.44	5	82

end targeted

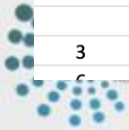
Ipi/Nivo

1 PhD's worth of literature search and reading to mitigate uncertainty in decision making
 2 countries >80,000 km Travel
 more than 100 hours filling in QOL questionnaires
 <80 imaging sessions >7000ml blood >12 biopsies
 3 treatments and 3 surgeries
 2 clinical trials including cross-over
 Diagnosed stage IIIc : 2008 , stage IIIB : 2009 Stage IV : 2011

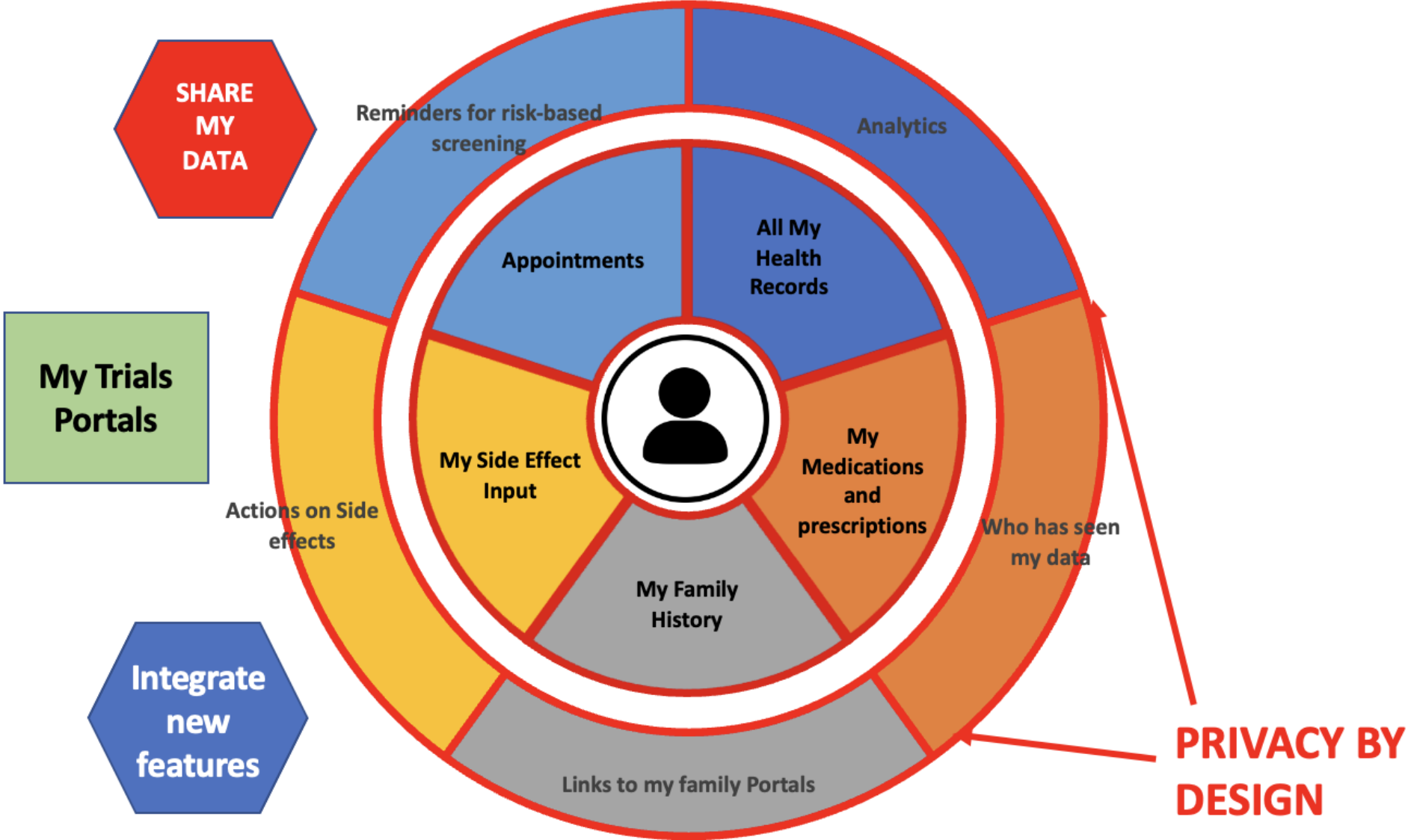
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MY HEALTH DATA PORTAL



Sync not Sunk : The case for a European Cancer Patient Digital Data Centre

Need:

- Patients want **Survival** with the best **Quality of Life** possible.
- When you are out of options you want upfront **access to the cutting edge**/best brains.
- Better informed decision making needs **quality, standardized data**.
- Not having **interoperability** and not **sharing** data, kills people.
- Relevant Research of **value to patients** and society.

Action:

- It will give patients **total EASY access to their own data** – for decision making and agency.
- It will enforce data standards and interoperability for **FAIR** data sharing.
- Good Secondary data use/**Research** - Data available, if not controlled by vested interest.
- The real **return on engagement** for patients is the opportunity to **initiate** research and collaborate when the value to them is proven.

THANK YOU FOR LISTENING

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