


SUDEP Action  
**NATIONAL CONFERENCE**

**Tackling epilepsy risk  
through innovation  
and collaboration**

**Dr Craig Newman  
Plymouth University  
7<sup>th</sup> July 2018**



#Prevent21  
Find out more at [www.sudep.org/prevent21](http://www.sudep.org/prevent21)


SUDEP Action, registered charity 1164250 (England & Wales), SC047223 (Scotland).  
Epilepsy Bereaved (founded 1995) is part of SUDEP Action.



**More than a research  
project**

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BEFORE EPSMON	EPSMON
No evidence based app for monitoring any chronic neurological illness - globally	Evidence based <b>system</b> for patient empowerment and self-managment
NHS Burden (£1.5bn) No NHS plan or national strategy	<b>FREE</b> to ALL PWE in the UK Additional research benefits
No structured clinical approach of assessment or communication	Overlapping clinical checklist and self-management app (EpSMon)



## Neglected risk

People with epilepsy are often either:


- **not seeing health professionals** for their epilepsy,
- **not discussing risk** during appointments or
- **not monitoring their risk** in-between appointments

**Result: More people with epilepsy are dying**



## Barriers to discussing risk

- No NHS plan to address
- No funding for core issues research



## Evolving NHS

- Healthcare crisis
  - Economy
  - Population
- Outdated model
- Transformation agenda
- 2020 digital target
- Epilepsy NEED

100+

95-99

90-94

85-89

80-84

75-79

70-74

65-69

60-64

55-59

50-54

45-49

40-44

35-39

30-34

25-29

20-24

15-19

10-14

5-9

0-4

Age Group	Male (%)	Female (%)
95-99	0.0%	0.0%
90-94	0.1%	0.2%
85-89	0.2%	0.5%
80-84	0.6%	0.9%
75-79	1.0%	1.4%
70-74	1.5%	1.8%
65-69	2.2%	2.4%
60-64	2.6%	2.8%
55-59	2.6%	2.7%
50-54	3.1%	3.2%
45-49	3.6%	3.7%
40-44	3.4%	3.5%
35-39	3.1%	3.2%
30-34	3.2%	3.2%
25-29	3.4%	3.4%
20-24	3.4%	3.3%
15-19	3.2%	3.1%
10-14	2.9%	2.7%
5-9	2.8%	2.7%
0-4	3.2%	3.1%



## NHS digital - challenges

- No digital prescribing model
- No carved out route to market
- Unclear efficacy model
- No mandating
- Resistant incumbents
- Procurement system requires a sales model



## Broader challenges

- Our relationship with Apps
- Too many voices, too many tunes
- Funding
- For FREE model
- Very small team tackling an international challenge

## Race to the moon

- Competitive and commercialised
- EpSMon versus the rest?
- Where to focus energy?
  - Marketing
  - Research
  - Tech development
  - Selling
  - .....

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## NIA - opportunity

  
*The***AHSN***Network* **England**  
NHS Innovation Accelerator

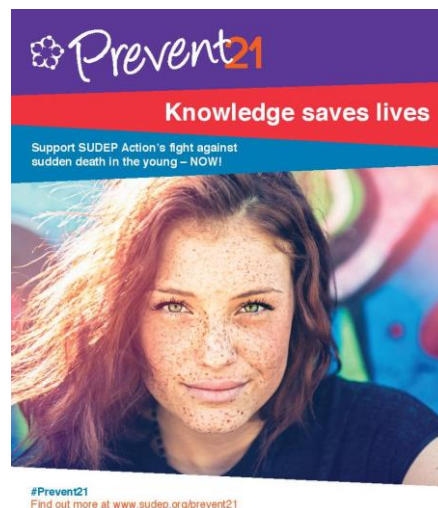
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## Future goals

- Capturing the impact of EpSMo
- Version 2 (Oct 2018)
- Living with epilepsy course
- Commercial model to sell into 1,700 GP practices (flag risk)
- Communicating risk research grant (£150k)
- Epilepsy Alliance campaign (Oct 2018)

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# THANK YOU!



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