

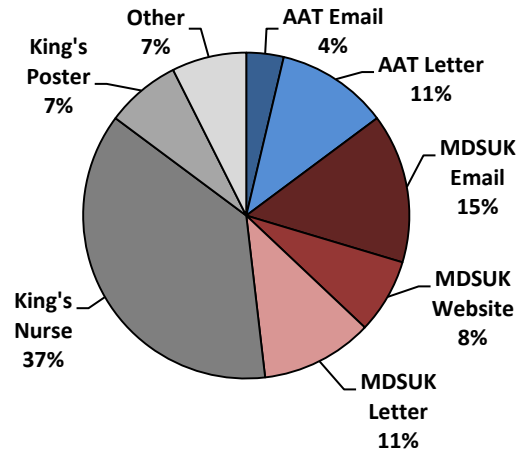
**MDS UK Patient Support Group**  
**Feedback: London Local AA/MDS Support Group Meeting 19/07/12**

**Attendees**

	<b>Attended*</b>	<b>Feedback</b>
<b>AA</b>	17 (33%)	11
<b>MDS</b>	34 (67%)	17
<b>Total</b>	<b>51</b>	<b>28</b>

\*Attendance figures depend on number of people who complete feedback/ sign in

**How did you hear about this regional meeting?**

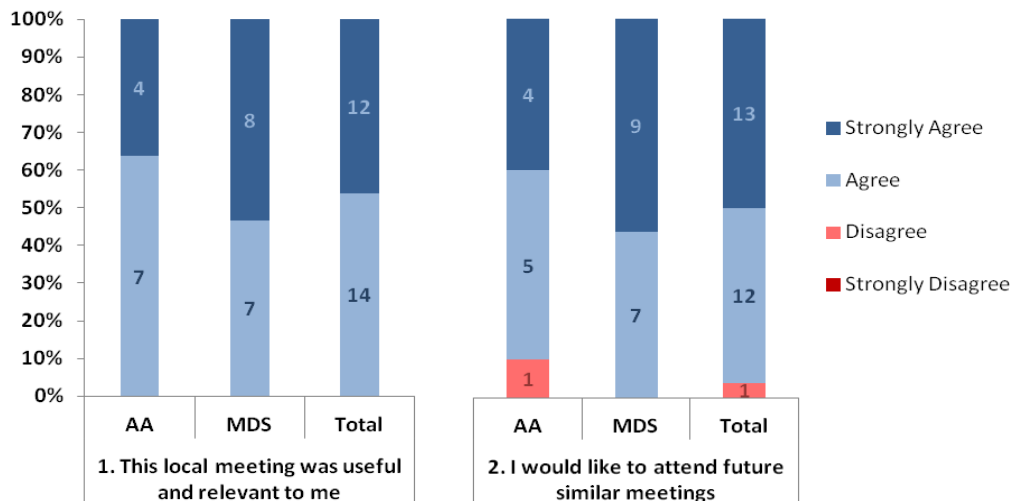


**Relevance and future attendance**

- 100% of respondents agreed they found the meetings useful and relevant.
- Overall majority (96%) of respondents agreed they would like to attend future similar meetings.

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<b>Total</b>	<b>No Response</b>
<b>1. This local meeting was useful and relevant to me</b>						
<b>AA</b>	36% (4)	64% (7)	0% (0)	0% (0)	100% (11)	(0)
<b>MDS</b>	53% (8)	47% (7)	0% (0)	0% (0)	100% (15)	(2)
<b>Total</b>	46% (12)	54% (14)	0% (0)	0% (0)	100% (26)	(2)
<b>2. I would like to attend future similar meetings</b>						
<b>AA</b>	40% (4)	50% (5)	10% (1)	0% (0)	100% (10)	(1)
<b>MDS</b>	56% (9)	44% (7)	0% (0)	0% (0)	100% (16)	(1)
<b>Total</b>	50% (13)	46% (12)	4% (1)	0% (0)	100% (26)	(2)

Percentage (and number) of people who responded to the above questions. Percentages do not take into account non-respondents.



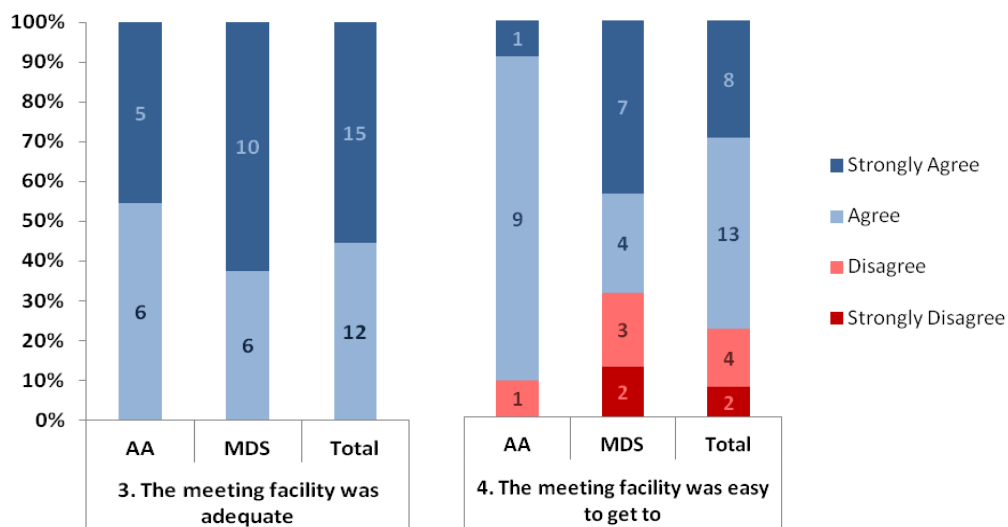
## Meeting facility

- 100% of respondents agreed the meeting facility was adequate, with the total majority (56%) strongly agreeing with this statement.
- 78% of respondents agreed the meeting facility was easy to get to. 91% of AA attendees agreed with this statement compared to 79% of MDS patients. More MDS patients from outside the immediate London postcode area chose to attend.

	Strongly Agree	Agree	Disagree	Strongly Disagree	Total	No Response
<b>3. The meeting facility was adequate</b>						
AA	45% (5)	55% (6)	0% (0)	0% (0)	100% (11)	(0)
MDS	63% (10)	38% (6)	0% (0)	0% (0)	100% (16)	(1)
<b>Total</b>	<b>56% (15)</b>	<b>44% (12)</b>	<b>0% (0)</b>	<b>0% (0)</b>	<b>100% (27)</b>	<b>(1)</b>

	Strongly Agree	Agree	Disagree	Strongly Disagree	Total	No Response
<b>4. The meeting facility was easy to get to</b>						
AA	9% (1)	82% (9)	9% (1)	0% (0)	100% (11)	(0)
MDS	44% (7)	25% (4)	19% (3)	13% (2)	100% (16)	(1)
<b>Total</b>	<b>30% (8)</b>	<b>48% (13)</b>	<b>15% (4)</b>	<b>7% (2)</b>	<b>100% (27)</b>	<b>(1)</b>

Percentage (and number) of people who responded to the above questions. Percentages do not take into account non-respondents.



## Joint AAT and MDS meetings

- 11% of respondents disagreed the joint AAT and MDS group set-up is of benefit. The remaining 89% agreed (59%) or strongly agreed (30%) the joint set-up is of benefit.
- 68% of respondents disagreed that they would prefer if the meetings were not mixed AA and MDS. A larger percentage of MDS attendees agreed with this statement (36%) compared to AA attendees (27%).
- High number of non responses to question 6 – should be considered the negative wording (i.e. agreeing/ disagreeing meetings are ‘not’ mixed) may be unclear.

	Strongly Agree	Agree	Disagree	Strongly Disagree	Total	No Response
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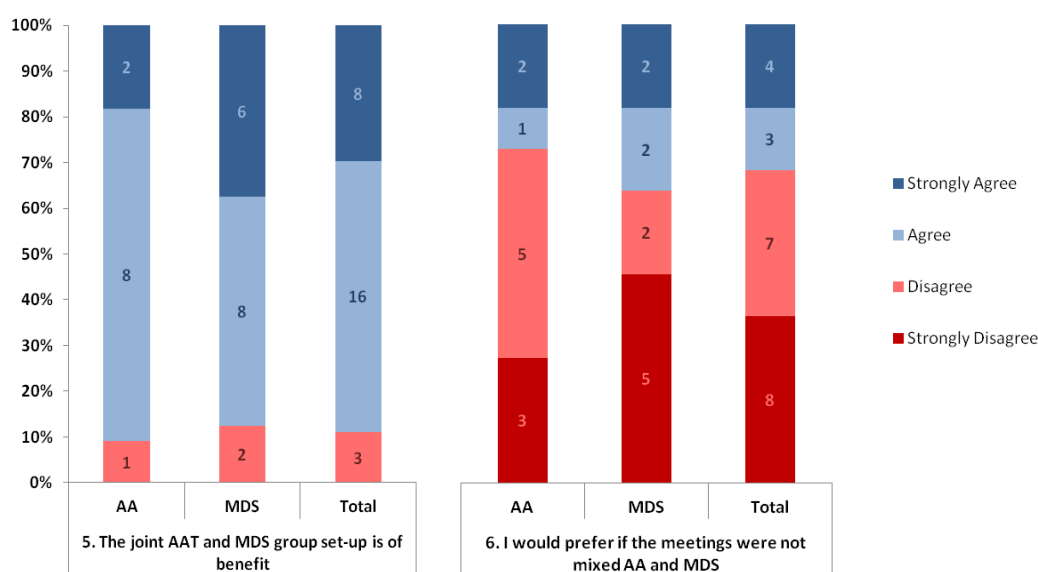
**5. The joint AAT and MDS groups set-up is of benefit**

<b>AA</b>	18% (2)	73% (8)	9% (1)	0% (0)	100% (11)	(0)
<b>MDS</b>	38% (6)	50% (8)	13% (2)	0% (0)	100% (16)	(1)
<b>Total</b>	30% (8)	59% (16)	11% (3)	0% (0)	100% (27)	(1)

**6. I would prefer if the meetings were not mixed AA and MDS**

<b>AA</b>	18% (2)	9% (1)	45% (5)	27% (3)	100% (11)	(0)
<b>MDS</b>	18% (2)	18% (2)	18% (2)	45% (5)	100% (11)	(6)
<b>Total</b>	18% (4)	14% (3)	32% (7)	36% (8)	100% (22)	(6)

Percentage (and number) of people who responded to the above questions. Percentages do not take into account non-respondents.



**Previous and other contact**

	AA		MDS	
	No	Yes	No	Yes
Have you attended a patient meeting before today?	73% (8)	27% (3)	56% (9)	44% (7)
Have you ever contacted MDS UK/AAT for advice and info?	82% (9)	18% (2)	47% (7)	53% (8)
Do you have access to the internet?	0% (0)	100% (11)	19% (3)	81% (13)
Have you visited the website (AAT/ MDS)?	27% (3)	73% (8)	25% (4)	75% (12)

**Do you use the MDS online patient chat forums?**

	MDS
<b>Never</b>	79% (11)
<b>Occasionally</b>	14% (2)
<b>Regularly</b>	7% (1)

**Taking part in local activities**

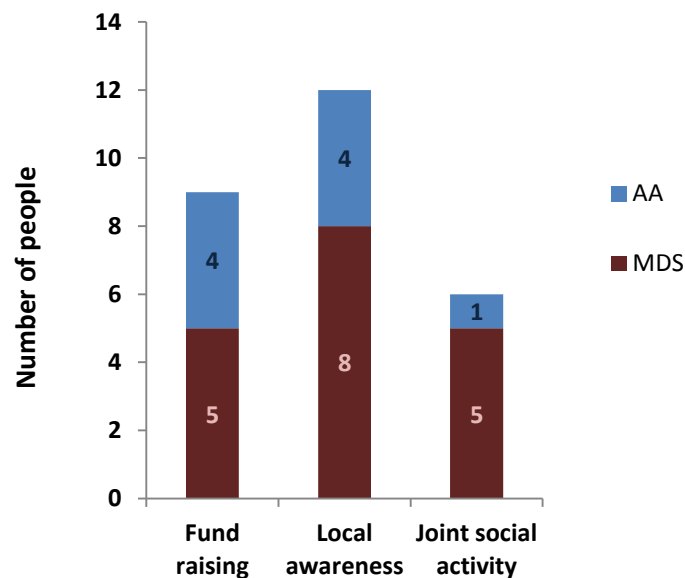
**Unable to take part:**

- “Unfortunately I have a very demanding job so unable to commit.”
- “Time permitting to hectic work schedule.”
- “It's great to have meetings - I just am unable to be an active participant.”
- “Sorry not very active, will look out for opportunities.”
- “Not sure, would like greater details of requirements.”

**Fundraising:**

- “We can't, due to age, be very active locally but would like to be informed of any fundraising locally.”
- “Fair/ bring and buy sale.”
- “Maybe a sale in the hospital X-mas fair/ cake stall.”

**I would like to take part in:**



**Topics for future meetings**

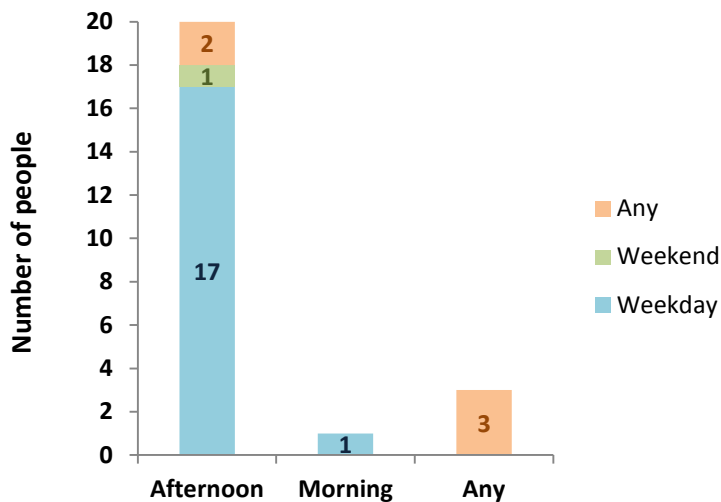
**Benefits and financial support:**

- “Discussion on benefit payments and prescription charges - why some pay, why others don't. Hospital parking free for cancer patients not for AA”
- “It would be great to have a themed meeting around benefits, free prescriptions etc, so that patients and families are aware of financial support available.”
- “Worth exploring if patients can arrange or facilitate accommodation.”

**Clinical:**

- “More information on trials and research, finance, benefits.”
- “Medical/ treatment issues.”
- “Updates/research/relevant topics (i.e. transplants, rights).”
- “Regular updates from expert speakers on latest research.”

**I would prefer to attend meetings:**



### **Additional comments and feedback**

- “More time for chat opportunity.”
- “Raise more awareness at local hospitals.”
- “Think it’s good to have shared AA/MDS meetings at least every other meeting as questions asked and answered are helpful to all.”
- “Pleased to see the MDS website and forum. Will be more active as a member and will do what I can to assist.”
- “I have found this meeting extremely useful and informative.”
- “Thank you for organising the day.”